A STUDY ON PSYCHOPATHOLOGY AND QUALITY OF LIFE IN CHILDREN WITH LEUKEMIA AND THEIR PARENTS

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CERTIFICATE

This is to certify that the dissertation entitled **"A STUDY ON PSYCHOPATHOLOGY AND QUALITY OF LIFE IN CHILDREN WITH LEUKEMIA AND THEIR PARENTS"** is a bonafide record of work done by **Dr.M.SOPHIA** in the Department of Psychiatry, Government Rajaji Hospital, Madurai Medical College, Madurai, under the direct guidance of me.

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CONTENTS

INTRODUCTION

Physical illnesses create psychological distress, both to the sufferer and to the caretaker. This is especially so, when the sufferer is a child. Prompt recognition and evaluation of psychiatric problems are essential, because psychiatric co-morbidity exacerbates the course of medical illness, causes significant distress to the patient, prolongs hospital-stay, and increases cost of care.

Owing to their developmental immaturity, children's conceptions of their bodies vary widely and are obviously influenced by experiences with illness. However in general, their ideas are governed by Piaget's developmental path of cognition and their understanding of their bodies corresponds to the stage of cognitive development.

During the sensorimotor stage (birth – 2 years), children's perception of their bodies and of their illness are primarily built on sensory experiences. During the preoperational stage (2-7 years) children tend to be aware of parts of the body, but have no real sense of organs, but conceptualize food and blood as going into and coming out of their bodies as if it was a container. They do not have a clear sense of cause and effect. In the concrete operational stage (7-11 years) children are able to apply logic, but this logic is literal and allows only one cause for an effect. They tend to be eager to learn factual information about their body. In the formal operational stage (11+ years) children are able to use

a level of abstract reasoning that allows discussion of systems rather than simple organs and can incorporate multiple causation of illness.

No pediatric patient can be considered in isolation from his or her parents as parents are the ones to whom the children look forward to, to understand the world in general and their illness in particular. It is from parent's reactions to illness or the treatment process, that the children understand how dangerous the illness could be and how they should optimally respond. Children who have a medical problem or who have a friend or family member with an illness come to know more about the body and its function. And, they often repeat what has been said to them without really understanding what it means. Hence, intervention procedures should be tailored to their level of understanding and they should be encouraged to explain in their own words about their illness or give their own versions of why something is happening.

Parents are usually the obligatory decision makers for the child, and thus are involved in all aspects of his or her care. Serious illness or prolonged treatment often results in significant emotional distress to the parents, impairing their ability to provide the necessary support and care to the child. Parental helplessness, anger, withdrawal, over-protectiveness and other emotional factors should be factored in to evolve an appropriate

therapeutic plan to address the emerging needs of both the children and their parents.

Chronic illnesses maimed the caretaker-adults much more than the children. Children are experienced as extensions of the self and responsible acceptance of the dependency entails apprehensions over the procedural pains, over eventual outcome and over developmental limitations. Their illness behavior was further vitiated by the non-scientific, culturally accepted health belief systems. Thus, diagnosis of Thalassemia might not cause so much panic as the diagnosis of ‘blood cancer’, because prevailing health belief systems envision the ‘blood cancer’ as ominous and near terminal. Apart from the emotional consequences, loss of working hours and income, apportioning the meager resources to meet the treatment expenses and inability to take care of other children and other needs of home and others imposed an overwhelming stress on the parents.

The effect of childhood cancer, compared to other physical illness, is more pervasive and profound. It confronts the child and the family with a new reality, one that includes the physical aspect (hospital, doctor, chemotherapy, radiotherapy, surgery) and the psychological one (trauma, loss, change, grief and in some instances death). The child and the family use coping mechanisms, which can be adaptive, or mal adaptive. The

ability of the child and the family to adapt to this new reality and the consequential life altering changes has a tremendous effect on the course of treatment.

Acute leukemia, especially acute lymphoblastic leukemia (henceforth referred as ALL), is the most common form of malignancy in childhood. It has a peak incidence between 2 and 6 years of age. ALL is more common in boys than in girls. The exact cause remains unknown, but a variety of possible factors have been proposed which includes genetic factors, environmental factors, viruses and immune deficiency states. In the past 30 years, there has been dramatic improvement in the management of ALL, and more number of children are in complete remission more than 5 years after the diagnosis. The most stressful periods in the management include the time of diagnosis, remission during the long term survival and death.

The present study thus aims to understand the psychological consequences of Acute Lymphoblastic Leukemia on the children and their parents, their coping skills and quality of life and their associations.

REVIEW OF LITERATURE

Psychological distress in response to serious pediatric illness has been a focus of many disease specific and non categorical studies over the years. Chronic illness differs from acute physical conditions in several important respects. A chronic illness is usually treatable but not curable. The onset of symptoms, the rigors of treatment and frequent absence from school make huge demands on the emotional and interpersonal resources of the children and their families.

Lavigne et al, (1992) reviewed 87 studies of children's adjustment to physical disorders like epilepsy, congenital heart disease, pediatric cancers, in a metaanalysis. Results indicate (a) children with such disorders show increased risk for overall adjustment problems, internalizing and externalizing symptoms; (b) risk was greatest in studies making comparisons to norms rather than to study controls; (c) risk varied by informant (teacher, mental health professional, parent), and by degree of matching with controls; (d) the self-concept of children with physical disorders across all studies appears significantly lower than that of healthy children, but the differences are not significant for studies with careful matching or comparisons with norms; (e) there are interdisease differences, but the number of studies within individual disorders, with a few exceptions, are quite small.

A two-part cross-sectional study set out to determine the frequency and nature of psychiatric disorder among children aged 7 to 12 years who were frequent attenders at one of two general practices found that Psychiatric disorders were common among 29% of the frequent attenders. Most of the psychiatric disorders were of an emotional nature (63%). (Bowman et al, 1993)

A recent review of empirical studies of pediatric heart transplant recipients found that 20%- 40% of these children experienced significant problems of psychological distress (Todaro et el, 2000).

Oguz et al evaluated the anxiety and depression in epileptic children to compare their results with that of a healthy control group and to determine the relationship of anxiety and depression scores to epilepsy-related factors. The State Trait Anxiety Inventory (STAI) and Children's Depression Inventory (CDI) were applied to 35 patients with epilepsy aged 9 to 18 years (mean age 12.9 ±2.52 years) and to 35 healthy children who served as the control group. The mean trait anxiety score was significantly higher in the epileptic patients than the corresponding control group.

Even in children undergoing a minor surgical procedure such as tonsillectomy, 17% had temporary symptoms of depression (Papakostas et al, 2003).

In some cases the effects can be longer lasting, as was found in a study of 5736 childhood cancer survivors studied young adults, reported more symptoms of depression than their sibling controls (Zebrack et al, 2002).

A cross-sectional diagnostic study in a pediatric outpatient clinic of 134 Children, aged 8 to 18 years, who were referred for unexplained chronic pain revealed that Psychiatric morbidity was present in 80% of the children (Antoinette et al, 2006)

Psychiatric assessment was done according to the DSM-IV TR criteria in 19 Children with predialysis chronic renal failure (CRF) and 19 children with End-stage renal disease on regular hemodialysis. The prevalence rate of Psychiatric disorders in all the studied patients were 52.6%. Adjustment disorders were the most common disorders (18.4%), followed by depression (10.3%) and neurocognitive disorders (7.7%). Anxiety and elimination disorders were reported in 5.1 and 2.6%, respectively. (Bakr, 2006).

Thirty nine children with transfusion dependent Thalassemia, were assessed for psychological problems and quality of life and it was found that 44% had psychological problems and 74% had a poor quality of life. Anxiety (67%), depression (62%) and conduct problems (49%) were the main findings. (Shaligram et al, 2007)

After the introduction of antiretroviral therapy, HIV infection in children has been transformed from an acute to a chronic illness. In a study by Rao et al (2007), a number of psychiatric illnesses including: depression, anxiety, disruptive disorders and hyperactive disorders have been observed in HIV-Infected children.

Thus, the studies on children with various physical illnesses indicate that, a significant number of them suffer from depression, anxiety disorders, disruptive and hyperactivity disorders commonly. The symptoms assessed in most of these cases would not necessarily meet criteria for a DSM diagnosis. However these symptoms do appear to be associated with decrease in function.

PSYCHOPATHOLOGY AMONG CHILDREN WITH ACUTE LYMPHATIC LEUKEMIA

Pediatric cancer presents a number of challenges to patients and their families. Clinically significant psychological distress has been reported in the children with cancer and their parents. (Magni et al, 1983; 1985).

Of the approximately 2000 cases of childhood malignancy diagnosed each year, three quarters of the cases are Acute lymphatic Leukemia (Altman et al, 1983). Pediatric ALL is now considered a chronic rather than an inevitably fatal disease, but it may still place these children at increased risk for development of psychological adjustment problems. (Pless et al, 1991; Lavinge et al, 1992). The life threatening nature of ALL, painful procedures and lengthy intensive treatment place considerable stress on the child and family, interfere with normal developmental tasks and add to the risk of developing adjustment problems (Koocher et al, 1986; Melman et al, 1986; Michael et al, 1987; Armstrong et al, 1992; Kupst et al, 1994;)

Parent, teacher, and self-report of 47 children and adolescents who had been receiving ALL therapy for at least one year or who were off therapy for no more than three years, were assessed using Behavioral

Assessment System for Children (BASC) to measure behavioral adjustment, Wechsler Intelligence Scale for Children-Revised (WISC-R) to measure cognitive abilities and Wide Range Achievement Test-Revised (WRAT-R) to measure academic abilities have shown that children with ALL are at risk for some behavioral adjustment problems, particularly anxiety, somatization, adaptability, attention, and withdrawal. Cognitive and academic abilities were associated with some dimensions of behavioral adjustment. (Moore et al, 2003)

Despite the numerous stressors some studies (Worchel et al 1988, Gizynski and Shapiro, 1990) have shown that children with cancer report fewer symptoms of depression than healthy school children or children with asthma. Phipps and Srivastava (1997; 1999) have explained that the children with cancer use an avoidant coping style to deal with their emotional response to cancer.

Sharan et al, (1999) interviewed 30 consecutive children aged 6-12 years using symptom checklist, children depression rating scale and the state trait anxiety inventory and found that 90 % of them had emotional disorders, which were mild to moderate intensity and was perceived to be treatable easily.

The coping and adaptation of 39 children, 6-12 years of age was studied using the Children's Apperception Test and was found that

disease awareness was present in 96%, expectation of a favorable outcome was held by 70% though 61% evidenced emotional distress. (Sharan et al, 1995)

A study on psycho social problems in families of children with cancer (Rajajee et al, 2007) included thirty four children with cancer and their parents. It was a prospective questionnaire based interview, which showed an increased incidence of behavioral problem in children, including Temper Tantrum, verbal and physical abuse of mothers.

Thus these studies on the psychopathology of children with leukemia indicate an increased incidence of behavioral problems, emotional distress and adjustment problems.

PSYCHOPATHOLOGY OF PARENTS OF CHILDREN WITH ALL

On the other hand parents of children with long term illnesses are under greater strain than other families (Copeland et al, 1993; Varni et al, 1996).

The diagnosis of chronic illness results in an overwhelming number of intense emotions. Shock, confusion, numbness, denial, anger and anxiety, guilt, self blame, fear, and helplessness, resentment and rejection are few examples (Kulhara et al, 1998). Chronic illnesses

negatively impact upon the parents, financially and emotionally (SatterWhite, 1978).

Studies on parents of children with cancer have reported the presence of prominent of psycho pathology, particularly depression in up to 85% of the parents (Magni et al, 1983, 1985; Maguire, 1980).

Depressive illness and anxiety states necessitating psychiatric treatment have been found in 20-30% of parents of children with leukemia. Parents also reported poor sexual and marital adjustment (Maguire, 1980).

A follow-up study in which the prevalence of emotional and behavioral problems among the siblings and parents of 42 children and adolescents treated for leukemia was compared with the prevalence of problems in a matched control group selected from the general population. The Achenbach Child Behavior Checklist, for completion by parents, and the Achenbach Child Behavior Checklist and Rutter B2 Behavioral Scale, for completion by teachers, were used to identify both social competence and behavioral problems. In addition, the Family Concept Inventory is used to evaluate the adjustment of families. The Leukemic children and adolescents were found to have significantly more problems and less social competence, particularly in school-related activities, than either the control group or their own siblings. There was

no difference in the prevalence of problems between the two groups of siblings, nor between the two groups of families. (Sawyer et al, 1986)

Magni et al (1988) evaluated psychological distress, social support and adjustment to disease of 69 parents of 35 children suffering from ALL and found that psychological distress of the mothers was negatively correlated with their child's adjustment to the disease.

A study on depression of parents of children with ALL by Iqbal and siddique (2002) has shown that depression was found in 56.7% of the parents. It was more common among mothers less educated parents and among those belonging to lower socio-economic class. Parents attributed their depression to multiple factors; most common were related to concerns about family's well being, financial constraints and distressing change in role and responsibilities.

Sharan et al (1989) have reported that 50% of the parents in their study had psychiatric disorders namely neurotic depression in 36.7% and adjustment disorder with depressed mood in 13.3%.

These studies on parents of children with leukemia indicate that a significant number of them were suffering from depression and anxiety disorders.

INDIVIDUAL AND FAMILY COPING

Coping can be defined as “thoughts and behaviors that the person uses to manage specific external or internal demands appraised as taxing or exceeding the resources of the individual” (Folkman et al, 1993).

Folkman (1986) identified 8 categories of coping styles – confrontative coping, distancing, self controlling, seeking social support, accepting responsibility, using escape-avoidance, planful problem solving, conducting positive reappraisal. Research has shown that individuals use multiple coping strategies in any given situation (Lazarus, 1999). Preferred coping styles often tied to personality variables; sometimes they can be viewed as traits as well as processes (Heim et al, 1997; Lazarus, 1999). A strategy that is initially effective in dealing with a stressor may longer be effective when the nature of the stressor changes (Penky et al, 2002).

Lipowski proposed that a patient’s choice of coping strategy was dependent on the underlying concept of the problem. In a study of 205 patients the descriptors ‘illness as challenge/acceptance’ and ‘illness as value’ were found to be related to ‘adaptive coping and mental well being’. Conversely, ‘illness as enemy’ or ‘illness as punishments’ was associated with psychological symptoms and mal adaptive coping (Shussler, 1992).

One way in which various coping styles can be organized is whether they are problem focused or active coping strategies and emotionally focused or avoidant coping strategies. When individuals appraise the situation as being changeable or within their control, they use problem focused coping styles (Shussler, 1992; Folkman et al, 1993) and where the situation is perceived as out of control, they use emotion focused strategies. In the medical setting, consulting psychiatrist can help change the patient's appraisal and encourage the patient to choose more adaptive coping strategies.

In Koocher and O'Malley's (1981) study, patient variables related to better adjustment and coping were young age at diagnosis, early knowledge of diagnosis, lack of relapses, type of cancer, short duration of treatment, lack of depression or anxiety and good self esteem.

Forty-three families of children with acute leukemia who participated in a prospective study of family coping were assessed to determine long-term coping. Data on coping were obtained through semi structured interviews, self-ratings (Current Adjustment Rating Scale), and ratings by project staff (Family Coping Scale). Results showed that these families showed significant improvements in adjustment over time. Antecedent variables related to coping were coping disposition (fathers), occupational level of fathers, and coping with earlier stages of the illness.

Concurrent/consequent correlates of coping were: level of family support, quality of the parents' marital relationship, good coping of other family members, lack of other concurrent stresses and open communication within the family. Medical status and duration of the illness were not significantly related to coping.(Kupst et al, 1988)

A cross-sectional investigation by Brown et al (1992) of the psychiatric and psychosocial functioning of 55 children diagnosed with acute lymphocytic leukemia and their families at three points in time: diagnosis (newly diagnosed), 1 year post diagnosis, and 1 year after the completion of chemotherapy (off-therapy). Results reveal minimal psychopathology in these children and their parents based on self- and informant-reports and structured diagnostic interviews. These families appear to be functioning adequately and report more family cohesiveness and marital satisfaction after chemotherapy was completed. Coping strategies commonly used by children and their parents include problem-solving, a positive outlook, and good communication.

In a study by Goldbeck (1998), 44 parents of children with ALL, answered mailed questionnaire about their own coping and their children’s coping. It showed that the dominant coping styles used were problem focused coping strategies in combination with optimistic basic attitude. Parents with mal adaptive coping reported low family cohesion

high depression and children with mal adaptive coping were socially withdrawn, more irritable, less optimistic, less competent as well as less compliant.

In a study by Melman et al (1998) a qualitative research method was used because this method enables a description of what it is like to live through childhood cancer in all its aspects. Parents whose child survived cancer were interviewed in depth about the late consequences of the disease. Results indicated that parents experienced changes of a definitive and long-lasting nature as a result of cancer in their child. In spite of the child's survival, feelings of loss and perseveration of problems prevailed. To cope with late sequelae, characteristic strategies were identified - including the position parents adopt a life or death perspective on the final outcome of the disease, the extent to which they express emotions, and the use of family planning and parenting behavior. Coping strategies used had not only an effect on the individual parent but also on the other family members. Parents who used coping strategies in a non extreme way appeared to be functioning well.

Patistea (2005) explored how parents perceived the child's leukemia and how well they were coping with it. Forty- one mothers and 30 fathers recruited from the largest Hellenic pediatric hospital were asked to answer closed and open-ended questions and to complete the

Coping Health Inventory for Parents [CHIP]. Most of the participants perceived the child's disease as a serious and threatening situation. The strategies aimed at maintaining family strength and an optimistic outlook were ranked as being the most helpful. Using specific criteria, it became evident that, overall, the subjects coped well. Neither gender nor spousal differences were found in the variables examined. Implications for health-related research, theory and practitioners are addressed.

Laura et al (2002) examined associations among several domains of executive function (working memory, behavioral inhibition, cognitive flexibility, and self-monitoring), coping, and emotional/behavioral problems in 30 children and adolescents ages 10- to 20-years old who had completed treatment for ALL and compared with 30 healthy controls matched on age and found that executive function impairment may be associated with difficulties in coping and emotion regulation.

A study by Earle (2007), on children's behavior following diagnosis of ALL showed that children in the 0-4 year age group adjusted well, owing to their limited understanding of their illness, 5-9 years age group were adjusting less well – experiencing social problems and worries about appearance. Older children 10- 14 years adjusted least well. Many withdrew socially and were concerned about the need to look and

feel normal. These findings will be useful for parents and clinicians in identifying typical behavior of children coping with ALL

Sharan et al (1995) studied the coping and adaptations of 30 parents of children with ALL a found that only 37% maintained an expectation of a positive outcome. This expectation of an unfavorable outcome and a mal adaptive coping style was associated with a higher psychiatric morbidity among the parents. A significant association between the presence of psychiatric disturbance and mal adaptive coping in the children and the parents were noted.

QUALITY OF LIFE

The past decade has produced significant improvement in the treatment and prognosis of ALL. As a result, a great deal of attention has been paid to the medical issues surrounding long term remission, such as the cessation of chemotherapy the possibility of a relapse, of a second malignancy or of problems in pregnancy on child bearing. Despite these concerns a number o studies have found that long term survivors tended to function well in school, work and in marriage. (Holmes, 1975; Fergusson, 1976; Li et al, 1976; Obez et al, 1980; Nagler, 1987)

Investigators at Dana Farber cancer center found that 53% of long term survivors were well adjusted. This also meant that 47% had at least

mild symptoms of emotional distress (Jaffe 1971; Koocher et al, 1979; 1981)

A 6 year follow up study by Kupst et al (1988) on long term coping with pediatric leukemia, found that families of children in long term remission continued to do well and even improved over time. The children were doing well medically and families had essentially returned to their normal activities and functioning.

Two follow up studies by Gray et al, 1992; Zevon et al, 1993 have demonstrated positive outcomes, such as lowered anxiety, closer family relationships, greater appreciation of life, improved value systems and increased altruism.

As part of a longitudinal study of family coping with pediatric leukemia, 28 former patients and their parents participated in a follow-up study at 10 years post treatment. Measures included the Current Adjustment Rating Scale, the Brief Symptom Inventory, the Ways of Coping Scale, the Family Coping Scale, and a semi structured interview. Long-term survivors and their parents continued to be well-adjusted to life post treatment. Coping and perceived adjustment in long-term survivors were positively related to socioeconomic status and mother's coping and negatively related to academic problems. A strong bidirectional relationship was found between survivors' and mother's

adjustment. Coping strategies were variable and not significantly correlated with coping adequacy or adjustment (Kupst et al, 1995).

This study underscores the importance of early assessment and correction of mal adaptive coping styles of parents and children for a better quality of life.

Among the most distressing aspects of childhood leukemia are the repeated invasive procedures. Parental distress specific to procedures remained relatively high and constant over the 2 to 3 years of treatment (Kazak et al, 1995). While the reduction of pain and anxiety during the procedures has been a successful area of psychological intervention, procedures continued to be among the most frequently distressing memories reported by survivors and their parents (Bush et al, 1994; Kazak, 1996).

Kazak et al (1997) evaluated relationships between parenting stress and parent-rated child quality of life during treatment for childhood leukemia and later parental posttraumatic stress symptoms and parent and child anxiety after completion of cancer treatment in 29 families of patients with leukemia. Correlations among in-treatment and off-treatment variables showed strong patterns of association between parenting stress during treatment and later parental adjustment, for both mothers and fathers. Parent-rated child quality of life was also

significantly associated with later adjustment for mothers and children. Despite the small sample, data point to the importance and consistency of parental reactions from diagnosis through the end of treatment and have clinical implications for psychosocial services during and after treatment.

Sawyer (1997) assessed 38 Children aged 2 to 5 years with cancer diagnoses and their parents immediately after diagnosis, 1 year after diagnosis, and 2 years after diagnosis. At each assessment, the psychological adjustment of the children and their families was compared with the adjustment of a cohort of children and families in the general community (n = 39). Children with cancer and their parents experienced significantly more emotional distress than children and parents in the community during the period immediately after diagnosis. However, the number of problems experienced by the children with cancer and their parents declined during the first year after the children's diagnosis and stabilized at a level comparable with that found among children and parents in the general community.

A longitudinal follow up study of 113 parents of children who were treated for leukemia, to evaluate prospectively the association between parental stress during treatment and posttraumatic stress symptoms (PTSS) after treatment ends, using self report questionnaires, showed that higher level of parenting stress during treatment was associated with

higher state anxiety after the child completed treatment and a significant association with post traumatic stress (Kazak 2007).

These studies suggest that evaluation of parenting stress early in the illness course and appropriate treatment and support can help the parents and children lead a better quality of life (Kazek 1997).

Various studies indicate the nature, intensity and multivarious dimensions of the psychopathology in the child-sufferers and how despite all the distress, they are able to adapt to a better level of living. The impact of the illness of the child and the responsibility of maintaining their physical and psychological equilibrium is on the parents. Investigations showed that despite significant life-events, they were able to lead a better quality of life because of the efficient use of coping mechanisms. But, such studies in the native setting are sparse. Such studies signify the variables a mental health professional has to address in an integrated approach to the problem. The near-absence of these studies is the stimulus and sets the directions for further explorations.

MATERIALS AND METHODS

AIM

The present study aims to assess the psychopathology among the children with ALL and their parents, including their Family burden, Quality of life, and coping and to infer their possible predictors.

OBJECTIVES:

1. To assess the frequency of psychopathology and psychiatric disorders among the children with ALL and their parents.
2. To determine the association between the psychopathology of the children and their parents,
3. To know the type of coping strategies used by the parents and their associations with psychopathology and quality of life.
4. To study the quality of life of the parents and their associations with psychopathology and coping strategies.
5. To understand the family burden, stressful life events and their associations with psychopathology and quality of life.

HYPOTHESES

The following hypotheses were formulated:

1. Children with ALL and their parents are more prone for psychiatric disorders.

2. Emotional disorders are more common among both children and their parents.
3. These disorders are mild to moderate in severity.
4. Greater the emotional disturbance in the children greater is the psychological distress in the parents.
5. Earlier age of onset and longer duration of illness is associated with greater psychopathology
6. The presence of other stressful life events increase the risk of psychiatric disturbances
7. Psychopathology is greater among the less educated parents and those belonging to the LSES
8. The quality of life of parents is more impaired when the child's quality of life is impaired.
9. Psychopathology is less in those who use a more adaptive way of coping.
10. The quality of life is better in those who use a more adaptive way of coping.

Setting

The study was conducted in the Department of Pediatrics, Govt Rajaji Hospital, Madurai, which is a teaching hospital; with tertiary core

facility. The project protocol received the approval of the Institutional Ethics Committee.

Period of study

The study was conducted during a period of six months from December 2007 to May 2008.

Research design

The study was a cross sectional evaluation of the psychological functioning of the children and their parents. As evidenced in the review, there are very few studies on the psychological aspects of ALL in South Tamil Nadu. Hence, the present study has been formulated on an **explorative design.**

Sample design

The study-population included 30 children with a diagnosis of Acute lymphoblastic Leukemia and their parents. The diagnosis was established on the basis of clinical and laboratory investigations by the Pediatric Consultant. The subjects were recruited randomly based on the following selection criteria.

Inclusion criteria

1. Children with a diagnosis of Acute Lymphatic Leukemia, during their hospital stay for chemotherapy.

2. Children between 5 and 12 years of age.
3. At least one parent who is available throughout the assessments.
4. Parents who consent to participate.

Exclusion criteria

1. Children with previous history of psychological morbidity such as mental retardation.
2. Children with history of other medical illnesses.
3. Family history of any other significant physical or psychological morbidity.
4. Very sick children.

Operational design

As all patients were in-patients, the details could be collected over two or more sessions so that motivation of the children was maintained. Children and the parents were seen separately at first and then conjointly. Considering due allowance for the ethnical variation, a pilot study was conducted and a proforma was prepared.

After a brief familiarizing session and knowing details of the illness and of the family, a written consent was obtained from the parents. The following instruments were administered.

Tools employed

1. A Semi structured proforma: Compiled for recording the socio demographic variables, birth, development, medical history, scholastic performance of the children, details about the illness – which includes illness duration, treatment regime, hematological indices and awareness about the illness. Parent's socio demographic variables, Medical history and awareness about their child's illness were also recorded.

2 .General health questionnaire – 28 [Goldberg, 1972]

It contains 28 items that have been divided into four subscales, each containing seven items.

A – Somatic symptoms

B- Anxiety/insomnia

C- Social dysfunction

D- Severe depression

The GHQ- 28 is the most well-known and popular version of the GHQ, which is used to detect psychiatric disorders in the general population and within community on non-psychiatric clinical settings such as primary care or general medical out – patients

3. Quality of life scale – WHO QOL – BREF [WHO, 2000]

The Australian WHOQOL-BREF contains 26 items. The instrument comprises one item from each of the 24 facets contained in the

WHOQOL-100, plus two items from the overall quality of life and general health facet. The WHOQOL-BREF was developed from the larger WHOQOL-100 data sets available from all WHOQOL centers to the Geneva coordinating centre. Like the WHOQOL-100, all items in the WHOQOL-BREF are rated on a 5-point scale. Overall the instrument shows good factor structure. Each of the four domains appears to be both sensitive to the health status of respondents, and sensitive to change in health status following treatment. All four domains demonstrate good internal consistency and excellent test-retest reliability. The physical and psychological domains in particular also demonstrate good construct validity.

4. Presumptive stressful life events scale (Singh et al, 1981)

Presumptive stressful life events scale (PSLES) consists of 51 life events. It is based on the Social Readjustment Rating Questionnaire by Holmes and Rahe (1967), which consists of 43 items or life events. This scale is especially prepared for the adult Indian population. It assesses the number of life events experienced in a lifetime, in the past one-year, frequency of occurrence of each event and quantitative estimate of presumptive stress of each of the life events. In our population, an average individual experiences an average of ten common stressful events in a life time without suffering any obvious adverse physical or

psychological disturbances. Similarly mean number of stressful events experienced over a period of one year without producing overt physical or mental illness is approximately two. In this study the patients were assessed if they had experienced any life event from the 51 items in the last one year prior to their presentation here and each life event was rated as present or absent. The Test-Retest reliability for the scale was found to be 0.73.

5. Family burden interview schedule [Pai and Kapur, 1981]

A tool to measure social burden on the families of patients, which measures seven subscales such as financial burden, disruption of family routine leisure, disruption of family interaction, effect on physical health of family members, effect on mental health of family members and subjective burden on a three point scale of severity

6. Ways of Coping (revised) [Folkman and Lazarus, 1985]

It is a 66-item questionnaire containing a wide range of thoughts and acts that people use to deal with the internal and or external demands of specific stressful encounters. The subject responds on a 4– point Likert scale (0- dose not apply/not used to 3 = used a great deal).

Using factor analysis, eight ways of coping are derived. They are confrontive coping, distancing, self controlling, and seeking social

support, accepting responsibility, escape – avoidance, planful problem solving and positive reappraisal.

7. Pediatric symptom checklist (Jellinek et al, 1998)

It is a psychosocial screen designed to facilitate the recognition of cognitive, emotional and behavioral problems in children. It consists of 35 items that are rated as never, sometimes or often present and scored 0, 1, and 2 respectively. There are two versions- a parent completed version and a youth self report. For children and adolescents ages 6 through 16, a cut off score of 28 or higher indicates psychological impairment. For children ages 4 and 5, the cut off score is 24 or higher (Little et al, 1994; Pagano et al, 1996). Test retest correlations across 4 weeks intervals for parent reports were 0.86 and 0.84in pediatric out patient samples. The PSC cut off score of 28 has a sensitivity of 95% and specificity of 68% when compared to clinician's ratings of children's dysfunction. (Murphy et al).

8. Children Depression Rating Scale (Poznanski, 1985)

It is a 16-item measure used to determine the severity of depression in children 6-12 yrs of age. Items are measured on 3, 4,5and6 point scales. The CDRS is derived from the Hamilton Rating Scale for depression (HAM-D); a score of 15 on the CDRS is equivalent to a score of 0 on the HAM-D. Assessment of information is based on parent, child

and schoolteacher interviews. Test retest correlation for the summary score across a 2-week interval was 0.80. Interrater correlation between 2 clinicians was 0.92. The CDRS-R score correlated 0.87 and 0.48 with clinician reported ratings of depression.

9. Children Global Assessment of Functioning Scale (Shaffer et al, 1983)

The CGAS is an adaptation of the global assessment scale for adults developed by Endicott et al 1976. It comprises one item that is rated on a hundred-point scale. For each deciles instrument contains behaviorally oriented descriptive examples. The CGAS has no subscales. Raters assign one score ranging from 1-100. Interrater intraclass correlations across raters at two occasions were 0.84 and 0.85. The CGAS correlated significantly with other clinician rated measures of impairments and correlations ranged from 0.76-0.92. a cut of value of 60 or lower is indicative of definite impairment.

10. Draw a Person Test (Koppitz, 1968)

The Human Figure Drawing Test is one of the most valuable techniques for evaluating children. It can be used both as a developmental test and as a projective method. It represents a graphic form of communication between the child and the examiner. The test requires the child to draw a whole person at the request of the examiner in his

presence. It can be administered as a group or individual test, though the individual test is often preferred as the child will be able to produce more revealing drawings in the one-one situations. The drawings will be scored for two different types of objective signs- The Developmental Indicators and The Emotional Indicators.

11. ICD 10 (WHO, 1992)

Instruments 2-6 were administered to the parents. Parents were also interviewed about their children using instruments 7-10. Children were administered the draw a person test. Whenever the child experienced difficulties or parent details were deferred for the next session.

STATISTICAL ANALYSIS

Analysis of the data was done using the measures of central tendency and dispersion such as the Mean, Standard Deviation, and Range. The associations between the variables were analyzed using Pearson's correlation.

RESULTS

TABLE 1 SOCIODEMOGRAPHIC AND ILLNESS VARIABLES OF THE CHILDREN

	NUMBER	% (N=30)
AGE: 5-7YEARS	13	43.33
7-10YEARS	14	46.60
ABOVE10	3	10.00
SEX: Boys	23	76.66
Girls	7	23.34
Domicile: Rural	24	80.00
Urban	6	20.00
Family type: Nuclear	25	83.33
Joint	5	16.67
Duration: < 4yrs	27	90.00
> 4yrs	3	10.00
Side effects: Absent	11	36.66
Present	19	63.34

Table 1 shows, the socio demographic details and disease related variables of the children. It was observed that two fifths of the children were between 5-7yrs of age and another two fifths were between 7-10yrs of age. Male children represented three fourths of the sample. Eighty per cent of the children were from rural background and majority was from nuclear families. The duration of illness was less than 4 years in 90% of the children and 63.34% had side effects such as alopecia and weight loss. All the families were from low socio economic status.

TABLE 2: MEASURES OF MEAN, STANDARD DEVIATION, RANGE AND CUT OFF SCORES OF THE VARIABLES OF CHILDREN

	MEAN	SD	RANGE Max-min	Children above cut-off No %
PSC	14.63	8.98	0-30	4 (13.33%)
CDRS	22.06	5.43	17-37	0 (0)
CGAS	65.10	7.99	40-75	13 (43.33%)
DAP	7.63	2.06	2-13	-

CUT OFF SCORES

PSC-Pediatric symptom check list - 28

CDRS-Children depression rating scale - 40

CGAS-Child global assessment of functioning scale - 70

DAP- Draw a person test. (Qualitative data, explained later)

It was observed that only 13.33% of the children scored above the cut off in PSC and none in CDRS, though only two fifths of the children functioned normally. Using ICD 10, 4 of the children met criteria for Oppositional defiant disorder (F91.3) and two of them met criteria for depressive conduct disorder (F92.0)

TABLE 3: EMOTIONAL INDICATORS IN DAP

S.No	Indicators	No observed N=30
1	Poor Integration of parts	10
2	Tiny figures	10
3	Transparencies	8
4	Slanting figures	6
5	Shading	6
6	Omission of Neck	4
7	Omission of parts	4
8	Asymmetry of parts	3
9	Monster figure	2
10	Genitals	1

Sum of indicators exceeds N as there were more than one indicators in each figure.

Qualitative analysis of Draw a Person test showed indicators of emotional disturbances among children with chronic illness. But, operationally defined quantitation of the scores did not correlate with any of the measures of psychopathology. Poor integration of parts, shading, tiny figures, transparency, absence of parts of body, and monster figures were the commonly observed emotional indicators among these children.

TABLE 4: CORRELATIONS BETWEEN MEASURES OF PSYCHOLOGICAL MORBIDITY AMONG CHILDREN AND DISEASE VARIABLES

	PSC	CDRS	CGAS	DAP
DUR	**0.37***	0.23	-0.08	-0.03
SE	0.08	0.20	-0.07	0.07
TR PH	0.21	0.09	-0.25	**0.38***

Values refer to Pearson's γ

Df = 28; p<0.05*; p<0.01**

PSC-Pediatric symptom check list
CDRS-Children depression rating scale
DAP- Draw a person test.
CGAS-Child global assessment of functioning scale
DUR- duration of illness
SE- Side effect
TR PH- treatment phase

Correlations between the children's psychopathology and their disease variables indicated that, the duration of the illness correlated positively with PSC. It was also observed that the treatment phase correlated positively with the children's psychopathology indicated by the Draw a person test.

TABLE 5: CORRELATIONS BETWEEN MEASURES OF PSYCHOLOGICAL MORBIDITY AMONG CHILDREN

	PSC	**CDRS**	**CGAS**	**DAP**
PSC	-	0.11	**-0.66****	0.21
CDRS	0.11	-	-0.26	0.12
CGAS	**-0.66****	-0.26	-	0.07
DAP	0.21	0.12	0.07	-

Values refer to Pearson's γ

Df = 28; p<0.05*; p<0.01**

PSC-Pediatric symptom check list
CDRS-Children depression rating scale
CGAS-Child global assessment of functioning scale
DAP- Draw a person test.

The correlations between the measures of the psychopathology among the children revealed that the scores on PSC correlated negatively with the scores on CGAS indicating that the children's functioning was significantly affected by the presence of psychopathology.

TABLE 6: MEASURES OF MEAN, STANDARD DEVIATION, RANGE AND CUT OFF SCORES OF THE VARIABLES OF PSYCHOPATHOLOGY OF PARENTS

VARIABLE	MEAN	SD	RANGE Max-min	Parents above cut off value No (%)
GHQ	46.43	9.89	28-71	30 (100)
OVER QOL	4.80	1.16	4-6	-
PHY HEALTH	43.47	10.61	17-57	27 (90)
PSY HEALTH	26.43	5.72	12-38	21 (70)
SOCIAL RELATIONS	35.73	12.26	8-50	28 (93)
ENVIRONMENT	39.00	6.88	28-50	25 (83)
PSLES	141.73	48.31	54-273	21 (70)
FAMILY BURDEN	25.43	7.66	12-45	-
COPING	59.83	9.49	32-76	-

	CUT OFF SCORES
GHQ- General Health Questionnaire	24
OVER QOL- overall quality of life	
PHY HEALTH- Physical health	28
PSY HEALTH- Psychological health	24
SOCIAL RELATIONSHIPS	12
ENVIRONMENT	32

PSLES- Presumptive stressful life events scale. > 2 life events per year

It was observed that all the parents had significant psychological problems as indicated by the scores on GHQ. However, nearly 80-90% of

them were found to have a better quality of life. Using ICD 10, 4 of the parents met criteria for Persistent somatoform pain disorder (F45.4) and 9 of them met criteria for Adjustment disorder with depressed mood (F43.2).

TABLE 7: CORRELATIONS BETWEEN MEASURES OF PSYCHOLOGICAL MORBIDITY AMONG PARENTS AND DISEASE VARIABLES

	GHQ	OV QOL	PH	PS H	SO RE	ENV	PSLES
DUR	0.09	-0.34	-0.22	-0.24	-0.14	-0.18	-0.02
SE	0.25	**-0.38***	-0.21	-0.21	-0.13	-0.25	0.33
TR PH	**0.46****	-0.35	-0.29	**-0.37***	-0.07	-0.33	0.29

Values refer to Pearson's γ

Df = 28; p<0.05*; p<0.01**

GHQ- General Health Questionnaire
OV QOL- overall quality of life
P H- Physical health
PS H- Psychological health
SO RE- Social relationships
ENV- Environment
PSLES- Presumptive stressful life events scale.

DUR- Duration of illness
SE- Side effect
TR PH- Treatment phase

Correlations of the parent psychopathology and the disease variables indicated that, the treatment phase correlated positively with the GHQ and negatively with psychological health domain of QOL. It was also observed that, the presence of side-effects correlated negatively with the overall QOL.

TABLE 8: CORRELATIONS BETWEEN MEASURES OF PSYCHOLOGICAL MORBIDITY AMONG PARENTS

	GHQ	OV QOL	PHY H	PSY H	SO RE	ENV	PSLES
GHQ	-	**-0.72****	**-0.77****	**-0.64****	**-0.46****	**-0.61****	**0.38***
OV QOL	**-0.72****	-	**0.76****	**0.59****	**0.55****	**0.71****	**-0.49****
PHY H	**-0.77****	**0.76****	-	**0.70****	0.32	**0.40***	-0.35
PSY H	**-0.64****	**0.59****	**0.70****	-	0.17	0.33	-0.01
SO RE	**-0.46****	**0.55****	0.32	0.17	-	**0.69****	**-0.50****
ENV	**-0.61****	**0.71****	**0.40***	0.33	**0.69****	-	**-0.37***
PSLES	**0.38***	**-0.49****	-0.35	-0.01	**-0.50****	**-0.37***	-

Values refer to Pearson's γ

Df = 28; p<0.05*; p<0.01**

GHQ- General Health Questionnaire
OV QOL- overall quality of life
PHY H- Physical health
PSY H- Psychological health
SO RE- Social relationships
ENV- Environment
PSLES- Presumptive stressful life events scale.

Correlation between measures of psychological morbidity among the parents indicates significant associations between many variables. Positive correlation exists between the scores in GHQ and PSLES. Negative correlations were observed between the overall QOL and the scores in GHQ and PSLES, indicating that the presence of psychopathology and stressful life events significantly affected the quality of life. Negative correlation also exists between the various domains of QOL with GHQ and PSLES. Also significant positive correlations exist among the various domains of QOL.

TABLE 9: CORRELATIONS BETWEEN MEASURES OF PSYCHOLOGICAL MORBIDITY AMONG PARENTS AND FAMILY BURDEN

	FB	FR	FL	FI	PHY H	PSY H	SB
GHQ	0.29	**0.40***	**0.36***	**0.63****	**0.55****	**0.48****	**0.47****
OVQOL	**-0.38***	**-0.55****	**-0.43***	**-0.58****	**-0.57****	**-0.44***	**-0.40***
PHY H	-0.19	**-0.38***	-0.18	**-0.48****	**-0.41***	-0.34	-0.33
PSY H	-0.25	-0.12	-0.09	-0.14	-0.11	-0.00	-0.11
SO RE	**-0.56****	**-0.66****	**-0.58****	**-0.66****	**-0.62****	**-0.56****	-0.33
ENV	**-0.54****	**-0.54****	**-0.62****	**-0.60****	**-0.51****	**-0.41***	**-0.51****
PSLES	0.08	**0.58****	**0.43***	**0.52****	**0.52****	**0.45***	**0.43***

Values refer to Pearson's γ
Df=28; p<0.05*; p<0.01**

GHQ- General Health Questionnaire
OV QOL- overall quality of life
PHY H- Physical health
PSLES- Presumptive stressful life events scale.
PSY H- Psychological health
SO RE- Social relationships
ENV- Environment

FB- Financial burden
FR- Family routine
FL- Family leisure
FI- Family interaction
PH- Physical health
PS H- Psychological health
SB- Subjective burden

Correlations between the measures of parent's psychopathology and Family burden indicate that, significant positive correlation exists between GHQ, PSLES and Family routine, Family leisure, Family interaction, Physical health, mental health of the family members and the subjective burden. The Financial burden of the family correlated negatively with overall QOL, social relationships and Environment domain of QOL. The physical health domain on QOL correlated negatively with family routine, family interaction and physical health of family members. The social relationships and environment domain of QOL correlated negatively with family routine, leisure, interaction, physical and mental health of the family members.

TABLE 10: CORRELATIONS BETWEEN MEASURES OF PSYCHOLOGICAL MORBIDITY AMONG PARENTS AND CHILDREN

	PSC	CDRS	CGAS	DAP
GHQ	**0.41***	-0.02	-0.07	0.16
OV QOL	**-0.56****	-0.06	0.19	-0.09
PHY H	-0.34	0.05	0.04	-0.05
PSY H	-0.15	-0.03	0.01	0.03
SO RE	**-0.47****	-0.13	0.07	-0.11
ENV	**-0.56****	-0.28	0.31	-0.08
PSLES	**0.41***	0.13	0.08	0.32

Values refer to Pearson's γ
Df = 28; p<0.05*; p<0.01**

PSC-Pediatric symptom check list
CDRS-Children depression rating scale
CGAS-Child global assessment of functioning scale
DAP- Draw a person test.

GHQ- General Health Questionnaire
OV QOL- overall quality of life
PHY H- Physical health
PSY H- Psychological health
SO RE- Social relationships
ENV- Environment
PSLES- Presumptive stressful life events scale.

The correlations between the measures of psychopathology among parents and children indicate that, the child's psychopathology as shown by the scores on PSC correlated positively with the parent's psychopathology as shown by the scores on GHQ. The scores on PSC also correlated positively with scores on PSLES and negatively with the overall QOL, social relationships and environment domains of QOL.

TABLE 11: CORRELATIONS BETWEEN MEASURES OF PSYCHOLOGICAL MORBIDITY AMONG CHILDREN AND FAMILY BURDEN

	PSC	CDRS	CGAS	DAP
F B	**0.47****	0.24	**-0.42***	-0.06
F R	**0.77****	0.21	**-0.47****	0.25
F L	**0.77****	**0.43***	**-0.56****	0.10
F I	**0.81****	-0.01	**-0.37***	0.20
PHY H	**0.70****	-0.17	-0.25	0.18
PS H	**0.72****	-0.12	-0.34	0.18
S B	**0.69****	**0.44***	**-0.56****	0.09

Values refer to Pearson's γ
Df = 28; p<0.05*; p<0.01**

PSC-Pediatric symptom check list
CDRS-Children depression rating scale
CGAS-Child global assessment of functioning scale
DAP- Draw a person test.

FB- Financial burden
FR- Family routine
FL- Family leisure
FI- Family interaction
PH- Physical health
PS H- Psychological health
SB- Subjective burden

Correlations between the measures of children's psychopathology and Family burden indicate that, the scores on PSC correlated positively with all the seven domains of Family burden scale. The scores on CDRS correlated positively with scores on family leisure and the subjective burden. Negative correlations were observed between the scores on CGAS and the financial burden, family routine, family leisure, family interactions and the subjective burden.

TABLE 12: CORRELATIONS BETWEEN MEASURES OF PSYCHOLOGICAL MORBIDITY AMONG PARENTS AND COPING

	CONF	DIST	SELF CONT	SOCIAL SUPP	ACC RESP	ESC AVD	PLAN PROB	POSI REAPP
GHQ	0.18	0.25	0.11	0.07	-0.01	0.31	0.13	0.11
OVER QOL	-0.29	-0.18	-0.27	0.05	0.07	-0.17	-0.10	-0.06
PHY HEALTH	-0.10	-0.20	-0.11	0.18	-0.03	-0.29	-0.13	-0.03
PSY HEALTH	-0.16	-0.10	-0.05	0.15	0.05	-0.01	0.03	0.05
SOCIAL RELAT	-0.11	**-0.36***	-0.06	-0.11	-0.08	-0.13	-0.25	-0.12
ENVIRON	-0.26	-0.28	-0.10	-0.16	0.09	-0.23	-0.10	-0.02
PSLES	0.19	0.19	0.29	-0.05	0.07	0.01	0.07	0.10

Values refer to Pearson's γ
Df = 28; p<0.05*; p<0.01**

GHQ- General Health Questionnaire
OVER QOL- overall quality of life
PHY HEALTH- Physical health
PSY HEALTH- Psychological health
SOCIAL RELATION- Social relationships
ENVIRON- Environment
PSLES- Presumptive stressful life events scale.
PP-Planful problem solving,
CONF-Confronting
DIST-Distancing
SC-Self controlling
SS-Social Support
AR-Accepting responsibility
EA-Escape avoidance
PR-Positive reappraisal

Correlations between the psychopathology of the parents and their coping skills, showed that, those who used distancing as a coping strategy found their social relationships to be poor, as indicated by the negative correlation between the two. No other significant correlations were observed.

TABLE 13: CORRELATIONS BETWEEN MEASURES OF FAMILY BURDEN AND COPING

	CONF	**DIST**	**SC**	**SS**	**AR**	**EA**	**PP**	**PR**
FB	0.20	**0.37***	0.12	**0.50****	0.15	0.22	**0.43***	**0.43***
FR	**0.37***	**0.41***	**0.39***	0.30	0.25	0.03	**0.39***	**0.47****
FL	**0.53****	**0.53****	**0.52****	**0.60****	0.24	0.22	**0.46****	**0.52****
FI	0.23	0.33	0.27	0.18	0.26	0.33	0.25	0.27
PH	0.18	**0.42***	**0.34**	0.20	0.27	0.31	0.33	0.31
PS H	0.19	**0.45***	**0.37***	0.27	0.34	0.27	0.32	0.30
SB	**0.39***	**0.41***	**0.39***	**0.47****	0.16	**0.36***	0.26	**0.36***

Values refer to Pearson's γ

Df = 28; p<0.05*; p<0.01**

FB- Financial burden
FR- Family routine
FL- Family leisure
FI- Family interaction
PH- Physical health
PS H- Psychological health
SB- Subjective burden

CONF-Confronting
DIST-Distancing
SC-Self controlling
SS-Social support
AR-Accepting responsibility
EA-Escape avoidance
PP-Planful problem solving
PR-Positive reappraisal

Significant positive correlations were observed between financial burden and confronting, distancing, social support seeking, planful problem solving and positive reappraisal. The family routine and leisure

correlated positively with confronting, distancing, self controlling, planful problem solving and positive reappraisal. In addition, the family leisure correlated significantly with social support seeking. Family interaction did not correlate significantly with any of the strategies. Physical health correlated with distancing. The mental health correlated with distancing, self controlling, planful problem solving and positive reappraisal. The subjective burden correlated positively with all strategies except accepting responsibility and planful problem solving.

DISCUSSION

Chronic illnesses of the adults are experienced by their families as distressing and disabling, but chronic illnesses in children are felt as disorganizing. Near-total dependency of the children, their vulnerability to stress and immaturity of their conceptualization of the illness and its consequences differentiate their problems from those of the adults. Leukemia is a chronic illness. Course of the illness, repeated chemotherapies with hospital-dependency, disturbances to the children's schooling and a questionable prognosis make them and their parents prone to continued stress for a long period. As there were no previous studies in the native population simultaneously focusing on the children and the parents, the present study was planned on an explorative design. The aim was to understand how the children were affected by Acute Lymphoblastic Leukemia and how their distress was experienced and coped with by their parents.

Thirty children and their parents were chosen on specific inclusion and exclusion criteria to identify a representative and homogenous population. All the children had been suffering from ALL for more than two years. Most belonged to the 5-10 yrs age group, were predominantly from rural domicile and all the families belonged to low economic status. Results showed that the sample population compared with those attending the Pediatrics Department of the hospital.

The tools used in the study were sought to understand and quantify both the distress and the extent of well being experienced by the children and their parents. Thus, PSC, CDRS and ICD-10 were used to measure the extent of psychopathology in children and Draw a Person test was used as a projective test to learn their body image disturbances and other psychological disturbances. CGAS was used to learn about the extent of well-being of the children. Among the parents, PSLES, Family Burden, GHQ and ICD-10 were used to know the nature and extent of psychopathology and QOL measured the extent of their well-being. To substantiate the clinical observation that the families were able to adapt well despite very severe stress, their methods of coping in the course of time were investigated using a 66 item Likert-type scale.

Clinically, the children exhibited many behavioral problems. Due to constant exposure to hospitals and treatment, the children were initially withdrawn. Later, they were hyperactive, rebellious and abusive, particularly of their mothers, both verbally and physically. This was similar to the findings of Sharan et al (1995), Moore et al (2003) and Rajajee et al (2007). Oppositional defiant disorder (F91.3) in four children and depressive conduct disorder (F92.0) in two children could be identified on fulfilling ICD-10 criteria, in our study. While Sharan et al (1995) had reported emotional disorders and Moore et al (2003) had

reported anxiety, somatization and adjustment problems. Despite the numerous stressors, the children in our study reported few depressive symptoms, which was also observed by Worchel et al (1988) and Shapiro et al (1990).

Draw a Person test can be used as a measure of intelligence, to know their body-image concept and as a projective test (Koppitz, 1968). Most children drew figures indicating age-related immaturity and scored poor IQs. None of the children had history of delayed developmental milestones or other indicators of mental retardation. The poor scores indicated how the illness and its consequences interfere with cognitive unfolding in these children. An operational method of quantification was attempted and the degree of disorganization increased during the phase of induction or relapse.

Psychopathological changes in the children were marked by significant disturbances in their level of functioning. Measures of distress in children indicated that four children scored above the cut-off in PSC, none of the children above the cut-off mark in CDRS and 13 children were above the cut-off scores in CGAS. Thus, it was evident that though many children evinced significant extent of disturbances, they were able to function well through family support.

Scores in PSC showed a significant inverse correlation to the CGAS which indicates that the presence of psychopathology affected their level of functioning in social and academic domains similar to that reported by Moore et al. Our study also found that longer the duration of the illness, higher was the psychological disturbances as indicated by the positive correlations between the scores in PSC and the duration of illness. Though DAP was a qualitative study, an attempted quantification correlated significantly with the treatment phase. Presence of side effects was not significantly related to any of the measures of pathology indicating the parental support and conducive environment.

The frequency of psychiatric disorders among half of the parents indicated the extent of distress experienced. Sharan et al (1999) and Iqbal et al (2002) had also reported similar results. Persistent Somatoform pain disorders, (F45.4) in six and adjustment disorder with depressed mood, (F43.2) in nine parents were the most common diagnosis observed in our study, while Sharan et al (1989), Magni et al (1983) and Iqbal et al (2002) reported Depression and Anxiety disorders as the most common disorders among the parents.

The distress was evident in the scores on various scales. Significance of the increased stressful life events was evident. Two thirds of the parents experience more than 2 stressful life events during the past

one year. In GHQ all the parents scored above the cut-off mark though significant numbers of them were found to evince a commendable quality of life in QOL scores. The results confirmed that though the parents were distressed enormously due to the illness of the child, they were able to effectively maintain their quality of life

On analyzing the correlations between the measures of parental psychopathology and the disease variables it was found that the presence of side effects like alopecia and weight loss significantly affected the overall quality of life of the parents. It was also found that the treatment phase, especially induction due to relapse, significantly affected the parent's psychopathology as indicated by the positive correlations with the scores in GHQ and negative correlations with the psychological health domain of QOL.

The presence of Psychological disturbances in the parents significantly lowered their quality of life as indicated by the negative correlations between GHQ and the various domains of QOL. It was also observed that more the number of stressful life events greater were psychological morbidity and poorer was the quality of life as indicated by the positive correlations between PSLES and GHQ and negative correlations with all domains on QOL.

Analysis of the correlations between the measures of parental psychopathology and family burden revealed that, the psychological distress of the parents and the presence of other stressful life events significantly affected the family's routine and leisure activities. It was also observed that the interaction among the family members and their physical and mental health was also significantly affected. The subjective burden on the family was thus found to be high. This in turn led to a poor quality of life of the parents. The financial burden of the family was high when the environment and social relationships of the family was poor.

The study found that the psychological distress of children as indicated by PSC, significantly correlated to most measures of parent psychopathology, quality of life and family burden. This finding reveals that it is the children's psychological functioning which is the important predictor of their parent's psychological functioning, quality of life and the burden on the family. CGAS scores indicating the well-being of the children are inversely related to the scores on Family burden, indicating that poorly functioning children increased the subjective burden of the family and also affected the family routine, leisure and interaction.

The Family structure in our society, passed on from ancient times, was a definite asset in the adaptive measures exhibited by the parents of the cancer children. This aspect was in contrast to western societies as

reported by Rajajee et al (2007). Even though most of the families in the study were from nuclear families, they were able to get the support of their relatives. There was both spiritual and psychological support from grand parents. Shared care was also an advantage as other siblings and household were looked after by caretakers like grand parents, aunts, and uncles etc.

Three fifths of the parents were using problem focused coping strategy like planful problem solving, social support seeking and positive reappraisal. One third used emotion-focused coping like confronting, self-controlling and accepting responsibility. Only 10% were using avoidant coping strategies like distancing and escape avoidance. Brown et al (1992) and Goldbeck et al (1998) have also reported that the commonly used coping strategies were problem solving, a positive outlook and good communication.

Analysis of the correlations between the measures of psychological morbidity of the parents and the methods of coping revealed that those parents whose social relationships were not adequate were using distancing as prominent coping strategy and those who had good social support were able to initiate a positive coping skill like positive reappraisal. Melman et al (1998) had reported that parents who used non extreme ways of coping were functioning well and Goldbeck et al (1998)

reported that those who used maladaptive methods of coping had significantly higher rates of depression. However such findings were not observed in our study.

Analyzing the correlations between family burden and the methods of coping, it was found that the financial burden of the family was increased when they were seeking social support in the form of professional help and when they were trying to solve the problem by one means or other. The family routine and leisure was affected when the parents were confronting the situation. Also when they were trying to control their emotions, or distance themselves from the situation the family routine and leisure activities were significantly affected. Further the physical and psychological health of the parents was disturbed when the parents used maladaptive coping methods such as distancing and self controlling. Finally the subjective burden of the family was high when the families used emotion focused coping strategies.

The study indicates that psychological distress is very high among both the children and parents of children with leukemia. Distress of the children is the essential and determining cause of parental distress, poor quality of life and family burden. On the other hand parental psychopathology affects their care giving abilities thereby affecting the children’s well being. Resilience of the parents in the face of distress

comes out markedly in the study and the findings would guide the mental health professional in positively managing the difficult Liaison-Psychiatry problem.

CONCLUSION

Our conceptualizations of chronic illnesses are thus changing. In addition to focusing purely on the medical management of Leukemia in the child, it would be worthwhile to focus attention on the extreme distress experienced by their parents. An empathic attitude towards their travails would go a long way in helping to reduce their distress. Appropriate psychiatric intervention would reduce the psychiatric morbidity in these parents. In addition to focusing on the negative aspects in their lives, one must realize that these people are living an apparently normal life in the face of extreme stress, thanks largely to inherent positive qualities within themselves. Encouraging Active Coping strategies and replacing avoidant ones would undoubtedly be of help. The important thing is to provide them with the hope and courage to bear what is eventually an unavoidable problem. Pediatricians who take care of chronically ill children are the professionals who first come into contact with these parents and it will be worthwhile if they spend some time in identifying those parents in distress and arranging for appropriate referrals so that the children they are treating are given better and less stressful family atmosphere. Hence psychiatrists and allied mental health professionals have a major role in alleviating the suffering of these parents. This can ultimately improve the compliance and hence life of these children

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APPENDICES

APPENDIX – 1 CONSENT FORM

JléRp T¼Ym

Gu ThPúUtT¼lé BWônf°Âu Jì Tá¾VôL EeLs áZkûRûV TÃúNô¾dLîm, EeLs TeúLtÀtám AòU¾ úLôì¸ú\u.

1. C¾p Teá ùTñYç êïYçm EeLÇu ùNôkR ÅìlTj¾táÃVç.
2. CRtá UñlTRu ØXúUô, C¾Äìkç ÅXáYRu ØXúUô EeLs áZkûRdá ¸ûPdL úYi¼V UìjçY °¸fûN êû\Âp GkR áû\TôúPô, UôñRúXô CìdLôç.
3. EeLû[l TtÈV ãV RLYpLs BWônf°dá UhåúU ETúVôLl TåjRlTåm Guñ Eñ¾ Ïñ¸ú\u.

Gu BWônf° Gu]ùYÉp

étñúSôVôp Tô¾dLlThP, áZkûRLs Utñm AYoL[ç ùTtú\ôoLÇu U]SXm TtÈ LiPÈYúR Bám. CRû], Jì úLsÅlTh¼VÄu ØXm EeLÇPêm, EeLs áZkûRÂPêm ùNnV Cìd¸ú\u.

Eñ¾ùUôÆ

¨eLs úUtÏÈV RLYpLû[T¼júRu. G]dá HtThP NkúRLeLû[EeLÇPm ùRÇîlTåj¾d ùLôiúPu. CkR BWônf°dá Gu TeLÇlûTëm Gu áZkûRûV TÃúNô¾dL AòU¾ûVëm êïU]çPu AÇd¸ú\u.

Sôs: ùTtú\ôo:

UìjçYo: áZkûR:

APPENDIX – 2

PROFORMA

NAME OF THE CHILD:

AGE : SEX: M/F

ADDRESS: RURAL/URBAN

RELIGION:

NAME OF FATHER: NAME OF MOTHER:

CONSANGUINITY: +/- DEG 2 /3 /4

FAMILY TYPE: NUCLEAR/ EXTENDED/ JOINT/ DISRUPTED

NO OF SIBLINGS: BIRTH ORDER:

FAMILY TREE:

BIRTH H/O:

1.Mother's condition during pregnancy: ill/well Details :
2. Drug Consumed if any:
3. Delivery: Full term/ preterm hosp/home Normal/CS/Instrumental
4. Birth weight: LBW/normal/not known
5. Neonatal complications: Asphyxia/ seizures/ jaundice/ others

DEVELOPMENTAL H/O :

1. Motor dev: normal/delayed
2. Speech dev: normal/delayed

MEDICAL HISTORY: Absent/Present

Injuries

Seizures

Meningitis

Any other major physical illness

Any physical anomaly

BEHAVIORAL DISTURBANCES: Absent/Present

SCHOOL: CLASS:

ACADEMIC PERFORMANCE: Good/ Average / Poor

H/O SCHOOL REFUSAL

DETAILS ABOUT THE CHILD'S ILLNESS

DIAGNOSIS:

DURATION OF ILLNESS:

TREATMENT H/O:

SIDE EFFECTS:

AWARENESS ABOUT THE ILLNESS:

TOTAL COUNT:

HB:

PLATELETS:

BLASTS:

FATHER'S NAME: AGE:

EDUCATION:

PRIMARY/SEC/HR.SEC/GRADUATE/UNEDUCATED

OCCUPATION:

UNSKILLED/SKILLED/PROFESSIONAL

INCOME:

H/O PHYSICAL ILLNESS:

H/O MENTAL ILLNESS:

H/O SUBS ABUSE:

MOTHER'S NAME: AGE

EDUCATION:

PRIMARY/SEC/HR.SEC/GRADUATE/UNEDUCATED

OCCUPATION:

UNSKILLED/SKILLED/PROFESSIONAL

INCOME:

H/O PHYSICAL ILLNESS:

H/O MENTAL ILLNESS:

ANY OTHER MEMBER SUFFERING FROM MEDICAL/ MENTAL ILLNESS:

AWARENESS ABOUT THE CHILD'S ILLNESS:

APPENDIX – 3

GENERAL HEALTH QUESTIONNAIRE (GHQ28) David Goldberg

Please read this carefully. We would like to know if you have had any medical complaints and how your health has been in general, over the past few weeks. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

Have you recently

A1. been feeling perfectly well and in good health?

a) Better than usual b) Same as usual

c) Worse than usual d) Much worse than usual

A2 been feeling in need of a good tonic?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

A3 been feeling run down and out of sorts?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

A4 felt that you are ill?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

A5 been getting any pains in your head?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than us

A6 been getting a feeling of tightness or pressure in your head?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

A7 been having hot or cold spells?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

B1 lost much sleep over worry?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

B2 had difficulty in staying asleep once you are off?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

B3 felt constantly under strain?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

B4 had been getting edgy and bad-tempered?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

B5 been getting scared or panicky for no good reason?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

B6 found everything getting on top of you?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

B7 been feeling nervous and strung-up all the time?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

Please turn over

Have you recently

Cl been managing to keep yourself busy and occupied?

a) More so than usual b) Same as usual

c) Rather less than usual d) Much less than usual

C2 been taking longer over the thing you do?

a) Quicker than usual b) Same as usual

c) Longer than usual d) Much longer than usual

C3 felt on the whole you were doing things well?

a) Better than usual b) About the same

c) Less well than usual d) Much less well

C4 been satisfied with the way you've carried out your task?

a) More satisfied b) About the same

c) Less satisfied than usual d) Much less well

C5 felt that you are playing a useful part in things?

a) More so than usual b) Same as usual

c) Rather less than usual d) Much less than usual

C6 felt capable of making decision about things?

a) More so than usual b) Same as usual

c) Rather less than usual d) Much less than usual

C7 been able to enjoy your normal day-to-day activities?

a) More so than usual b) Same as usual

c) Rather less than usual d) Much less than usual

Dl been thinking of yourself as a worthless person?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

D2 felt that life is entirely hopeless?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

D3 felt that life isn't worth living?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

D4 thought of the possibility that you might make away with yourself?

a) Definitely not b) I don’t think so

c) Has crossed my mind d) Definitely has

D5 found at times you couldn't do anything because your nerves were too bad?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

D6 found yourself wishing you were Dead and away from it all?

a) Not at all b) No more than usual

c) Rather more than usual d) Much more than usual

D7 found that the idea of taking your own life kept coming into your mind?

a) Definitely not b) I don’t think so

c) Has crossed my mind d) Definitely has

A	B	C	D	Total

APPENDIX - 4

PRESUMPTIVE STRESSFUL LIFE-EVENTS SCALE

(Singh et al, 1981)

1. Death of spouse (95)
2. Extra marital relation of spouse (80)
3. Marital separation / divorce (77)
4. Suspension or dismissed from job (76)
5. Detention in jail of self or close family member (72)
6. Lack of child (67)
7. Death of close family member (66)
8. Marital conflict (64)
9. Death of friend (61)
10. Robbery or theft (59)
11. Excessive alcohol or drug use by family member (58)
12. Conflict with in-laws (57)
13. Broken engagement or love affair (57)
14. Major personal illness or injury (56)
15. Son or daughter leaving home (55)
16. Financial loss or problems (54)
17. Illness of family members (52)
18. Trouble at work with colleagues, superiors or subordinates (52)
19. Prophecy of astrologer or palmist etc. (52)
20. Pregnancy of wife (wanted or unwanted) (52)
21. Conflict over dowry (self or spouse) (51)
22. Sexual problems (51)
23. Self or family member unemployed (51)
24. Lack of son (51)

25. Large of loan (49)
26. Marriage of daughter or dependent sister (48)
27. Minor violation of law (48)
28. Family conflict (47)
29. Break up with friend (47)
30. Major purchase or construction of house (46)
31. Death of pet (44)
32. Failure in examination (43)
33. Appearing for examination or interview (43)
34. Getting married or engaged (43)
35. Trouble with neighbour (40)
36. Unfulfilled commitments (40)
37. Change in residence (40)
38. Change or expansion of business (37)
39. Outstanding personal achievement (37)
40. Begin or end schooling (36)
41. Retirement (35)
42. Change in working condition or transfer (33)
43. Change in sleeping habits (33)
44. Birth of daughter (30)
45. Gain of new family member (30)
46. Reduction in number in family functions (29)
47. Change in social activities (28)
48. Change in eating habits (27)
49. Wife begins or stops work (25)
50. Going on pleasure trip or pilgrimage (20)

Total Score: Total No. of events :

APPENDIX - 5

Ways of Coping (revised) [Folkman & Lazarus 1985]

The Ways of Coping (Revised) is a 66 item questionnaire containing a wide range of thoughts and acts that people use to deal with internal and/or external demands of specific stressful encounters.

The revised Ways of Coping (Folkman & Lazarus, 1985) differs from the original ways of coping checklist (Folkman & Lazarus, 1980) in several ways. The response format in the original version was Yes/No; on the revised version the subject responds on a 4 point Likert scale (0 = does not apply and/or not used; 3 = used a great deal). Redundant and unclear items were deleted or reworded, and several items, such as prayer, were added.

Table 1

Empirically constructed Scales from the WAYS OF COPING (Revised)

(Community Sample)

To score the scales, sum ratings for each scale.

Scale 1: Confrontive coping

46. Stood my ground and fought for what I wanted.
77. Tried to get the person responsible to change his or her mind.
17. I expressed anger to the person(s) who caused the problem
28. I let my feelings out somehow.
34. Took a big chance or did something very risky.
6. I did something which I didn't think would work, but at least I was doing something

Scale 2: Distancing

44. Made light of the situation; refused to get too serious about it.
13. Went on as if nothing had happened.
41. Didn't let it get to me; refused to think too much about it.
21. Tried to forget the whole thing.
15. Looked for the silver lining, so to speak; tried to look on the bright side of things.
12. Went along with fate; sometimes I just have bad luck.

Scale 3: Self-controlling

14. I tried to keep my feelings to myself.
43. Kept others from knowing how bad things were.
10. Tried not to burn my bridges, but leave things open somewhat.
35. I tried not to act too hastily or follow my first hunch.
54. I tried not keep my feelings from interfering with other things too much.
63. I thought about how a person I admire handle this situation and used that as a model.
64. I tried to see things from the other person's point of view.

Scale 4: Seeking social support

8. Talked to someone to find out more about the situation.
31. Talked to someone who could do something concrete about the problem.
42. I asked a relative or friend I respected for advice.
45. Talked to someone about how I was feeling.
18. Accepted sympathy and understanding from someone.
22. I got professional help.

Scale 5: Accepting responsibility

9. Criticized or lectured myself.
29. Realized I brought the problem on myself.
51. I made a promise to myself that things would be different next time.
25. I apologized or did something to make up.

Scale 6: Escape-Avoidance

58. Wished that the situation would go away or somehow be over with.
11. Hoped a miracle would happen.
59. Had fantasies or wishes about how things might turn out.
33. Tried to make myself feel better by eating, drinking, smoking, using drugs or medication, etc.
40. Avoided being with people in general.
50. Refused to believe that it had happened.
47. Took it out on other people.
16. Slept more than usual.

Scale 7: Planful problem-solving

49. I knew what had to be done, so I doubled my efforts to make things work.
26. I made a plan of action and followed it.
1. Just concentrated on what I had to do next – the next step.
39. Changed something so things would turn out all right.
48. Drew on my past experiences; I was in a similar situation before.
52. Came up wit a couple of different solutions to the problem.

Scale 8: Positive reappraisal

23. Changed or grew as a person in a good way.
30. I came out of the experience better than when I went in.
36. Found new faith.
38. Rediscovered what is important in life.
60. I prayed.
56. I changed something about myself.
20. I was inspired to do something creative.

APPENDIX - 6

Family burden interview schedule [Pai and Kapur 1981]

A tool to measure social burden on the families of psychiatric patients instructions:

To the relatives: We are trying to assess the various difficulties felt by the family of a psychiatric patient and will ask you a few questions in the direction. Please do not hesitate to express your true feelings.

To the raters: Please interview the relative on the following guidelines. You may probe further in order to assess a particular item, if you feel the need to do so. Note your rating for each general category as well as for each individual item therein, on a three point scale.

Severe - 2
Moderate - 1
Nil - 0 as and when you interview.

After completing the interview please assess the burden on the family as a whole and give the rating on similar 3 point scale.

A. Financial Burden:

1. Loss of Patient's Income: (Whether he has lost his job? Stopped doing the work which he was doing before?) (Completely, partially, not at all?) (To what extent it affects the income of the family?) Severely, moderately, not at all.
2. Loss of income of any other member of the family due to patient's illness. (Whether any one has stopped working in order to stay home, has lost pay? Has lost job? Due to any other reason connected with patient's illness? (How much does it affects the family finances?) Severely, moderately, not al all.

3. Expenditure incurred due to patient's illness and for his treatment. (Has he spend or lost money irrationally for which his illness is the cause? How much has this affected the family finances?) (How much money had been spent on treatment, medicines, transport, accommodation in different city, etc.) (How much has been spent on other treatment such as temples, native healers, etc.?) (How much does this affect the family finances?) Severely, moderately, not at all.
4. Expenditure incurred due to extra arrangements (for any other relative to come and stay with patient, for appointing a nurse or a servant, for keeping children in boarding etc.)
5. Loans taken or spent the savings (How much loan? How do they plan to pay it back? How much does it affect the family?) Severely, moderately, not at all. (Whether they spent from savings? Were they exhausted? How much is the family affected by this?) Severely, moderately, not at all.
6. Any other planned activity put off because of financial pressure of patient's illness (like postponing a marriage or trip as a religious rite which would have needed finance)

B. Disruption of Family Routine Activities:

1. Patients not going for work, school, college, etc. (How much inconvenient it is to the family) (Severely, moderately, not at all.)
2. Patient's lack of help in the household work (How much does it affect the family?) (Severely, moderately, not at all.)
3. Disruption of activity of other members in the family (whether some one has to spend more time on looking after patient, and abandon

some other routine activity) (How much does it affect the family?) Severely, moderately, not at all.

4. Disruption of activities caused by patient's behaviour, (Patient insisting on some one being with him, not allowing the person to go out etc., patient becoming violent, & breaking up things, patient not sleeping and not allowing others to sleep) (How much does it affect the family?) Severely, moderately, not at all.
5. Any other member missing school, meals because of neglect caused by patient's illness. (How much time does it affect the family?)

C. Disruption of Family Leisure:

1. Stopping of normal recreational activities (Completely, partially, not at all) (How do the family members take it?)
2. Patient's illness exhausted other persons leave and leisure time (How is this person affected by it?)
3. Patient's lack of attention to other members in the family such as children.
4. If any other leisure activity had to be abandoned due to patient's inability or illness (Any pleasure trip planned or family fathering etc.) (How do the family members feel about it?)

D. Disruption of Family Interaction:

1. Any ill effect on general atmosphere of the house (Has it become dull, quiet, lot of misunderstandings, etc.) (How do they view it?)
2. If other members get into arguments due to this (Such as how to treat him? Who is to blame etc., Who should do the work?) How does it affect them? Severely, moderately, not at all.

3. If the relatives and neighbours have reduced or stopped visiting or interacting with the family (because of patient's behaviour, or stigma attached to his illness) How do they feel about it?
4. If the family has become secluded and avoid mixing with others (Because they feel ashamed or that they feel people may misunderstand them etc.) How do they feel about it?
5. Any other event on relationship of family members as well as neighbours and relatives (such as separation of spouses, quarrels between two families, property feuds, police intervention, embrassment for family members, etc.) How do they feel about it.

E. Effect on Physical Health of Others:

1. Has any other member of the family suffered physical ill health, injuries, etc. due to patient's behaviour (How has it affected them?)
2. Any other adverse effect on others health. (Some one losing weight, someone exacerbating already existing illness etc.)

F. Effect on Mental Health of Others:

1. Has any other member sought help for psychological illness (Eg. Shock of patient's suicide bid or disobedience or worries about patient's future etc.)
2. Has any other member lost sleep, become depressed, enough to cry often, expressed suicidal wishes, become excessively irritable etc.)
3. Is there any other burden felt regarding which we have not asked you about? Yes, No. If yes what.
4. How much does it affect you, severely, moderately, not at all.

G. Subjective Burden:

To be assessed by asking a standard question to the relative of patient and rating as reported.

Q. How severely would you say you have suffered due to patient's illness, severely, a little, not at all?

Severely - 2

A little - 1

Not at all - 0

APPENDIX - 7

WORLD HEALTH ORGANIZATION

QUALITY OF LIFE

WHOQOL-BREF

Australian Version (May 2000)

The WHOQOL-BREF produces a profile with four domain scores and two individually scored items about an individual's overall perception of QOL and health (Q1 and Q2). The four domain scores are scaled in a positive direction, with a score range of 0-100, and with higher scores denoting higher QOL. So too, the two individual items assessing overall QOL are scaled in a positive direction, with a score range of 1-5, and with higher scores denoting higher QOL. Methods for obtaining domain scores are presented below. A computer diskette containing the necessary algorithms for computing domain scores, based on SPSS, is supplied together with this manual.

Calculating raw domain scores

Raw domain scores are calculated by straightforward summative scaling of constituent items. Three negative worded items need to be reverse-scored (Q3, Q4 and Q26), as shown in the formulae.

The raw domain scores are calculated as follows:

Physical health	= (6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18
Psychological health	= Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)
Social relationships	= Q20 + Q21 + Q22
Environment	= Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25

Because each domain comprises a different number of items, the upper and lower possible raw score and the overall raw score range differs for each domain. These values, which are required in calculating transformed scores, are shown in Table.

Table

Lower and upper raw values and possible raw score range for each of the domains of the Australian WHOQOL-BREF

Domain	Lower Value	Upper Value	Possible score range
1. Physical	7	35	28
2. Psychological	6	30	24
3. Social relationships	3	15	12
4. Environment	8	40	32

Transforming raw domain scores to 0-100 scale:

Raw domain scores need to be transformed to a 0-100 scale, for ease of comparison with other data sets. This transformation converts the lowest possible score to zero and the highest possible score to 100. Scores between these values represent the percentage of the total possible score achieved. The values shown in Table are used in calculating the transformed scores.

Raw scores are transformed using the following formula:

$$\text{Transformed score} = \frac{\text{(actual raw domain score-lowest possible raw domain score)}}{\text{Possible raw domain score range}} \times 100$$

Please read each question and assess your feelings, for the last two weeks, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very Dissatisfied	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
2.	How satisfied are your with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the **last two weeks**

		Not at all	A Small amount	A Moderate Amount	A great deal	An Extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4.	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	Slightly	Moderate	Very	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

		Not at all	Slightly	Somewhat	To a great extent	Completely
10.	Do you have enough energy for every day life?	1	2	3	4	5

11.	Are you able to accept you bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information you need in your daily life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Not at all	**Slightly**	**Moderate**	**Very**	**Extremely**
15.	How well are you able to get around physically?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the **last two weeks**

		Very Dissatisfied	**Fairly Dissatisfied**	**Neither Satisfied nor Dissatisfied**	**Satisfied**	**Very Satisfied**
16.	How satisfied are your with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5
20.	How satisfied are you with your personal relationship?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you	1	2	3	4	5

with your transport

		Never	Infrequently	Sometimes	Frequently	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

APPENDIX - 8

PEDIATRIC SYMPTOM CHECKLIST

Please mark under the heading that best describes your child:

		Never	Sometimes	Often
1. Complains of aches and pains	1	_____	_____	_____
2. Spends more time alone	2	_____	_____	_____
3. Tires easily, has little energy	3	_____	_____	_____
4. Fidgety, unable to sit still	4	_____	_____	_____
5. Has trouble with teacher	5	_____	_____	_____
6. Less interested in school	6	_____	_____	_____
7. Acts as if driven by a motor	7	_____	_____	_____
8. Daydreams too much	8	_____	_____	_____
9. Distracted easily	9	_____	_____	_____
10. Is afraid of new situations	10	_____	_____	_____
11. Feels sad, unhappy	11	_____	_____	_____
12. Is irritable, angry	12	_____	_____	_____
13. Feels hopeless	13	_____	_____	_____
14. Has trouble concentrating	14	_____	_____	_____
15. Less interested in friends	15	_____	_____	_____
16. Fights with other children	16	_____	_____	_____
17. Absent from school	17	_____	_____	_____

18. School grades dropping 18 _____ _____ _____

19. Is down on him or herself 19 _____ _____ _____

20. Visits the doctor with

doctor finding nothing wrong 20 _____ _____ _____

21. Has trouble sleeping 21 _____ _____ _____

22. Worries a lot 22 _____ _____ _____

23. Wants to be with you

more than before 23 _____ _____ _____

24. Feels he or she is bad 24 _____ _____ _____

25. Takes unnecessary risks 25 _____ _____ _____

26. Gets hurt frequently 26 _____ _____ _____

27. Seems to be having less fun 27 _____ _____ _____

28. Acts younger than children

his or her age 28 _____ _____ _____

29. Does not listen to rules 29 _____ _____ _____

30. Does not show feelings 30 _____ _____ _____

31. Does not understand other

people's feelings 31 _____ _____ _____

32. Teases others 32 _____ _____ _____

33. Blames others for his

or her troubles 33 _____ _____ _____

34. Takes things that do not

belong to him or her 34 _____ _____ _____

35. Refuses to share 35 _____ _____ _____

Total score _____

Does your child have any emotional or behavioral problems for which she or he needs help? ( ) N ( ) Y

Are there any services that you would like your child to receive for these problems? ( ) N ( ) Y

If yes, what

services?_____

_____

Pediatric Symptom Checklist (PSC)

APPENDIX - 9

CHILDREN'S DEPRESSION RATING SCALE (CDRS)

The Children's Depression Rating Scale (CDRS) is a 16-item measure used to determine the severity of depression in children 6-12 years of age.

Items are measured on 3-, 4-, 5-, and 6-point scales. The CDRS is derived from the Hamilton Rating Scale for Depression (HAM-D); a score of 15 on the CDRS is equivalent to a score of 0 on the HAM-D.

Assessment information is based on parent, child and schoolteacher interviews.

1. **Depressed Mood** (0-5). Affect may be aroused (e.g., sad, forlorn, gloomy, anguished) or suppressed. Note nonverbal behavior (e.g., facial expression, eye contact, body posture). Child may or may not verbalize feelings of sadness.

0=No information

1=Definitely not depressed-facial expression and voice animated during interview

2=Doubtful-mild suppression of affect during interview and/or some loss of spontaneity

3=Mild-overall some loss of spontaneity. Child looks unhappy during parts of interview. May still be able to smile when discussing

non threatening areas

4=Moderate-may have a moderate restriction of affect throughout most of the interview and have brief periods where looks unhappy

5=Severe-child looks sad, withdrawn with little verbal interaction throughout interview. May look like crying

2. **Weeping** (0-3). Information usually from parents, teachers, but occasionally from child.

0=No information

1=Normal for age

2=Suggestive statements that child cries more frequently than peers

3=Cries frequently-more than reasonable for age or provocation

3. **Self-Esteem** (0-5). The child's ability to describe self is very concrete at 6 and 7, becoming more sophisticated at 9 and 10. Note affective tones around the child's responses. Inappropriate guilt rates 3 or 4.

0=No information

1=Child describes self in mostly positive terms

2=Doubtful evidence of lowered self-esteem

3=Child describes self using a mixture of attributes, with both affectively positive and negative tones

4=Child uses both affectively positive and negative terms, but preponderance of negative attributes, or if concept understood, gives minimal bland answers

5=Child either refers to self in derogatory terms (e.g., unpleasant nicknames) or completely avoids any question dealing with selfconcepts, self-image, or self-esteem

4. **Morbid Ideation** (0-4).

0=No information

1=None expressed

2=Some morbid thoughts-all related to a recent reality event

3=Admits to morbid thoughts on questioning, but does not dwell on them, or parents report morbid thoughts of child

4=Death themes spontaneously discussed or elaborate and extensive morbid ideation

5. **Suicide and Suicide Ideation** (0-5).

0=No information

1=None

2=Has thoughts about suicide-usually when angry

3=Recurrent thoughts of suicide

4=Thinks about suicide and names methods or if depressed, strongly denies thinking about suicide

5=Suicide attempt within the last month or actively suicidal

6. **Irritability** (0-5). Information usually from Parents, nurses, etc., and direct observation. This can range from whining, “chip on the shoulder” attitudes to temper outbursts and other direct displays of hostility and anger. Rate on frequency of irritable behavior. Some children may directly display whining, irritable behavior during the interview.

0=No information

1=Normal

2=Occasional-slightly more than normal

3=Episodic

4=Frequent

5-Constant

7**. Schoolwork** (0-5). Consider current function as opposed to usual or expected function. Expected function should take into

consideration the intelligence of the child and specific learning disabilities, cultural and family expectations.

0=No information

1=Performing at or above the expected level.

3=”Not working to capacity” or recent disinterest in schoolwork with minimal interference with performance

4=Doing poorly in most subjects or evidence of a recent major interference with performance

5=Incapable of doing productive schoolwork at time of rating

8. **Capacity to have fun** (0-5). Often reflected in hobbies and interests outside of school.

0=No information

1=Child’s interests and hobbies appropriate for age, personality, and environment. No appreciable change during present illness

2=Child has interests-hobbies outside of school, but activities mainly passive. Shows some interest but not enthusiasm

3=Child easily bored. May frequently complain of nothing to do or child expresses interest and hobbies which are realistically unavailable to the child

4=In structured activities, may “go through the motions” without

real interest or enthusiasm

5=Child doesn't take initiative to involve self in any activities. Tends to passively watch others or watch TV. Takes pushing and coaxing to involve in any activities.

9. **Social withdrawal** (0-5).

0=No information

1=Enjoys good friendships with peers at school and home or never has had adequate peer relationships

2=Child names several friends, but relationships sound meager or has one or two friends, but not able to integrate into larger peer group

3=Child changes from actively seeking out friendships to a passive role (i.e., waits for others to initiate a relationship). Observes rather than participates in groups unless pushed

4=Child frequently rejects opportunities for seemingly desirable interaction with other children

5=Child does not relate to other children. Either states he has "no friends" or actively rejects former friends and any new children

10. **Expressive Communication** (0-3). Refers primarily to possible psychomotor retardation of language. Rate on the quantity and quality of verbal material. Consider the cultural background and intelligence of the child in the interview situation

0=No information

1=Normal

2=Doubtful-mild. Monotonous voice. Mild delay in answering questions. Gives monosyllabic or short answers in all areas of interview

3=Moderate-severe. Same as (1) except delay in answering questions prolongs the interview. Even greater reduction in verbal content, may also have poverty of facial expression

11. **Sleep** (0-3). This information usually most reliable from child interview.

0=No information

1=No difficulty or occasional difficulty sleeping

2=Mild-frequent difficulty sleeping. Child and/or parent may report this

3=Moderate-difficulty with sleeping nearly every night. May be evidence of sleep deprivation (e.g., child looks tired)

Circle if difficulty with sleep is:

0=No information/does not apply

1=Initial

2=Middle

3=Early morning wakening

13. **Frequent Physical Complaints** (0-4). Child may complain of stomach pains, headaches, or other bodily aches and pains. Rate frequency. Parents and nurses generally more reliable.

0=No information

1=No complaints

2=Occasional complaints. Child is easily reassured

3=Frequent complaints, but can be distracted or reassured (e.g., school phobic who feels fine if allowed to stay home from school)

4-Preoccupied with aches and pains, may keep child from other Activities

14**. General Somatic** (0-3).

0=No information

1=Normal

2=Occasional complaints of fatigue

3-Frequent-complains of being tired, doesn't feel like doing things used to enjoy

15. **Hypoactivity** (0-3). Consider current activity level as opposed to usual activity level. Check with parents, school teachers, nurses

0=No information

1=Activity at usual level

2=Minimal retardation activity

3=Talks slowly, walks slowly, slow to move during play

16. **Reversal of Affect** (0-2).

0=No information

1=No

2=Yes

17. **Disturbance of Eating Pattern** (0-3).

0=No information

1=No problem

2=Mild. Mother complains of change in eating pattern or chronic problems with food, either some variety of “poor eater” or overeats

3=Moderate. More severe disturbance of eating pattern. If undereats, accompanied by weight loss. If overeats, has moderate obesity. May steal and hoard food or show more bizarre pattern such as eating out of garbage cans. Unable to follow a medically necessary diet prescribed by a physician

APPENDIX - 10

Children's Global Assessment of Functioning (GAF) Scale

Adapted from the Global Assessment Scale for Adults

Children's Global Assessment Scale- Shaffer et al 1229

Rate the subject's most impaired level of general functioning for the specified time period by selecting the lowest level which describes his/her functioning on a hypothetical Continuum of health-illness. Use intermediary levels (e.g. 35, 58,62). Rate actual functioning regardless of treatment or prognosis. The examples of behavior provided are only illustrative and are not required for a particular rating.

Specified Time Period: 1 month

91-100

Superior functioning in all areas (at home, at school, and with peers); involved in a wide range of activities and has many interests (e.g. has hobbies or participates in extracurricular activities or belongs to an organized group such as Scouts, etc): likeable, confident; "everyday" worries never get out of hand; doing well in school; no symptoms.

81-90

Good functioning in all areas; secure in family, school, and with peers; there may be transient difficulties and "everyday" worries that

occasionally get out of hand (e.g. mild anxiety associated with an important exam. occasionally 'blowups" with siblings parents, or peers)

71-80

No more than slight impairment In functioning at home, at school; or with peers; some disturbance of behavior or emotional distress may be present in response to life stresses (e.g. parental separations, deaths, birth of a sib), but these are brief and interference with functioning is transient; such children are only minimally disturbing to others and are not considered deviant by those who know them.

61-70

Some difficulty in a single area, but generally functioning pretty well (e.g. sporadic or isolated antisocial acts, such as occasionally playing hooky or petty theft; consistent minor difficulties with school work; mood changes of brief duration; fears and anxieties which do not lead to gross avoidance behavior; self doubts);has some meaningful interpersonal relationships; most people who do not know the child well would not consider him/her deviant but those who do know him/her well might express concern.

51-60

Variable functioning with sporadic difficulties or symptoms in several but not all social areas; disturbance would be apparent to those

who encounter the child in a dysfunctional setting or time but not to those who see the child in other settings

41-50

Moderate degree of interference in functioning in most social areas or severe impairment of functioning in one area, such as might result from, for example, suicidal preoccupations and ruminations, school refusal and other forms of anxiety, obsessive rituals, major conversion symptoms, frequent anxiety attacks, poor or inappropriate social skills, frequent episodes of aggressive or other antisocial behavior with some preservation of meaningful social relationships

31-40

Major impairment in functioning in several areas and unable to function in one of these areas, e.g. disturbed at home, at school, with peers or in society at large, e.g., persistent aggression without clear instigation; markedly withdrawn and isolated behavior due to either mood or thought disturbance, suicidal attempts with clear lethal intent: such children are likely to require special schooling and/or hospitalization or withdrawal from school (but this is not a sufficient criterion for inclusion in this category)

21-30

Unable to function in almost all areas, e.g., stays at home, in ward, or in bed all day without taking part in social activities or severe impairment in reality testing or serious impairment in communication (e.g., sometimes incoherent or inappropriate)

11-20

Needs considerable supervision to prevent hurting others or self (e.g. frequently violent, repeated suicide attempts) or to maintain personal hygiene or gross impairment in all forms of communication, e.g. severe abnormalities in verbal and gestural communication, marked social aloofness, stupor, etc.

0-10

Needs Constant supervision (24-hr care) due to severely aggressive or destructive behavior or gross impairment in reality testing, communication, cognition, affect, or personal hygiene

APPENDIX - 11

DRAW A PERSON TEST
LIST OF EMOTIONAL INDICATORS ON HFD'S OF CHILDREN
(All of the emotional indicators are considered valid for boys and girls aged 5-12 unless otherwise indicated)

Quality Signs

1. Poor integration of parts of figure (boys 7, girls 6)
2. Shading of face
3. Shading of body and/or limbs (boys 9, girls 8)
4. Shading of hands and/or neck (boys 8, girls 7)
5. Gross A symmetry of limbs
6. Slanting figure, axis of figure tilted by 15 degrees or more
7. Tiny figure, 2 inches high or less
8. Big figure, 9 inches or more in height (boys and girls 8)
9. Transparencies

SPECIAL FEATURES

10. Tiny head, head less than $1/10^{th}$ of total figure in height
11. Crossed eyes, both eyes turned in or out
12. Teeth
13. Short arms, arms not long enough to reach waistline
14. Long arms, arms long enough to reach knee line
15. Arms clinging to side of body
16. Big hands as large as face of figure
17. Hands cut off, arms without hands or fingers
18. Legs pressed together
19. Genitals
20. Monster figure
21. 3 or more figures drawn spontaneously
22. Clouds, rain, snow

OMISSIONS

23. No eyes
24. No nose (boys 6, girls 5)
25. No mouth
26. No body
27. No arms (boys 6, girls 5)
28. No legs
29. No feet (boys 9, girls 7)
30. No neck (boys 10, girls 9)

Figure 1

This figure was drawn by a 6 year old male child suffering from the illness for the past 1year. The child met ICD criteria for Oppositional Defiant disorder. The PSC score was 19, CDRS was 17 and CGAS was 61%. The drawing shows the following features:

1. Poor Integration of parts of Figure: This is associated with instability, a poorly integrated personality, poor coordination or impulsivity, immaturity due to developmental lag, neurological impairment, regression due to serious emotional disturbance or all of these.

2. Tiny Figure: This emotional indicator reflects extreme insecurity, withdrawal and depression. It also indicates feelings of inadequacy, a shrunken Ego, concern over dealing with the environment.

3. Shading: is a manifestation of Anxiety.

4. Omission of Body: Among school age children this is a sign of serious psychopathology indicating, mental retardation, cortical malfunctioning, severe immaturity due to developmental lag and emotional disturbance with acute body anxiety and castration fears.

5. Omission of Neck: Considered Normal up to the age of 9 for girls and 10 for boys. It indicates immaturity, impulsivity and poor inner control.

FIGURE 1

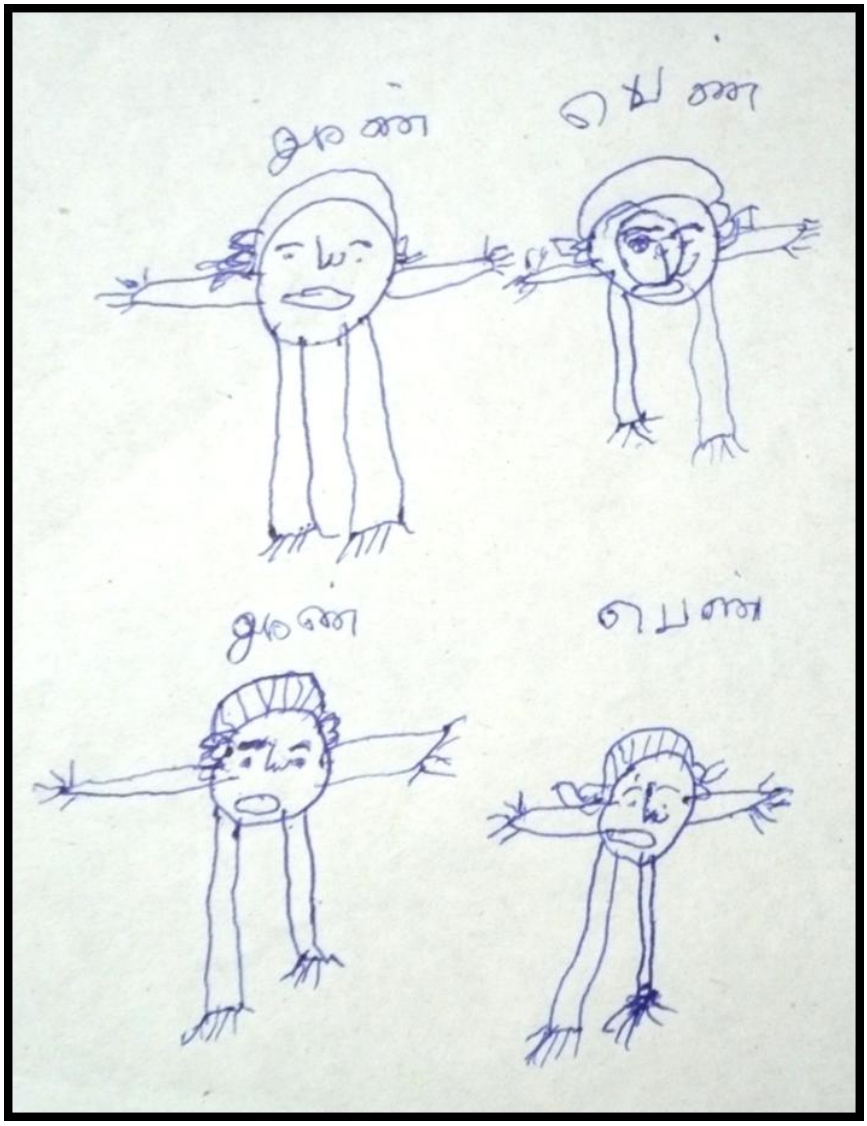

Figure 2

This figure was drawn by a 7 year old male child, suffering from the illness for past 2 years and currently in the relapse phase. The child had symptoms of irritability, anger outbursts, adamant behavior and defiant behavior. The PSC score was 22, CDRS was 18 and CGAS was 60%. The drawing shows following features:

1. Tiny Figure: This emotional indicator reflects extreme insecurity, withdrawal and depression. It also indicates feelings of inadequacy, a shrunken Ego, concern over dealing with the environment.

2. Slanting Figure: Not associated with any specific type of behavior but rather suggests general instability and lack of balance.

3. Transparencies: These are associated with immaturity, impulsivity, and acting out behavior.

4. Hands cut off: This reflects feelings of inadequacy or guilt over the failure to act correctly or over the inability to act at all.

5. Omission of Neck: Considered Normal up to the age of 9 for girls and 10 for boys. It indicates immaturity, impulsivity and poor inner control.

FIGURE 2

Figure 3 & 4

These were drawn by a 7 year old male child, suffering from the illness for past 3 years, currently relapsed. The child met ICD criteria for Oppositional Defiant Disorder. The PSC score was 30, CDRS was 18 and CGAS was 60%. The drawings reveal the following features:

1. Poor Integration of parts of figure.

2. Transparencies.

3. Monster or Grotesque Figure: figure representing non human, degraded or ridiculous person. It reflects feelings of inadequacy and very poor self concept. Children who draw human monsters or artifacts like robots seem to perceive themselves as different from others, as not being quite human.

4. Genitals: This was found in the drawings of children who were overtly aggressive. It is a sign of serious psychopathology involving acute body anxiety and poor impulse control.

5. Asymmetry of arms.

6. Omission of arms, legs and neck.

FIGURE 3

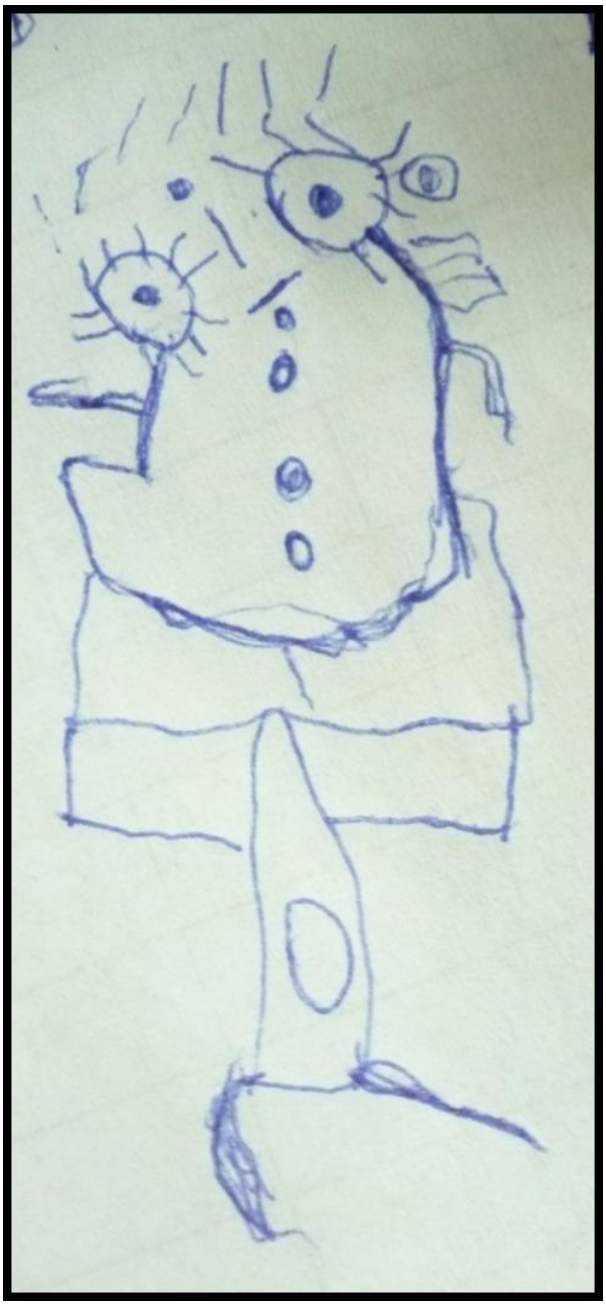

FIGURE 4

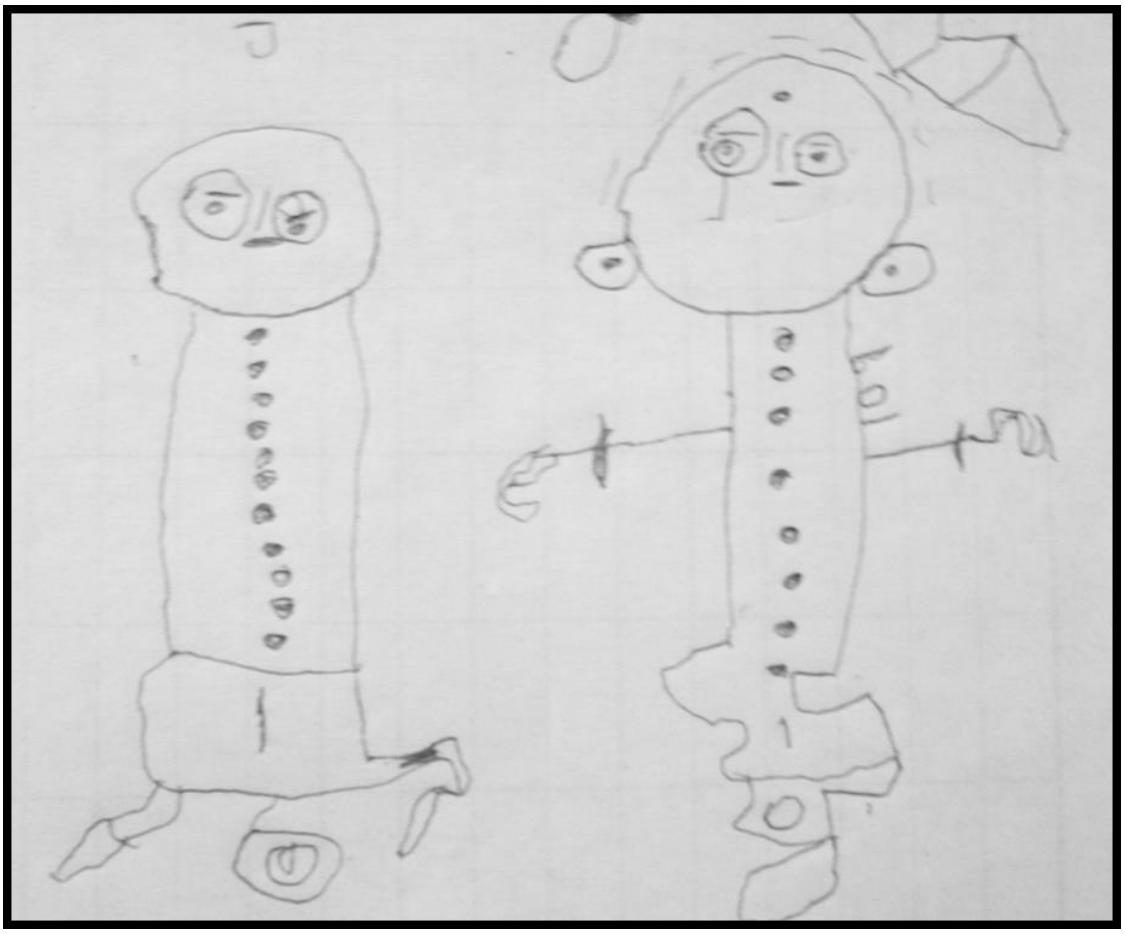

Figure 5 & 6

These were drawn by an 8 year old male child suffering from the illness for past 1 year currently on maintenance regime. The PSC score was 23, CDRS was 29 and CGAS was 53%. The child met ICD criteria for Depressive conduct disorder. The drawings reveal the following features:

1. Transparencies.
2. Shading.
3. Slanting Figures.
4. Omission of neck.
5. Omission of nose.

FIGURE 5

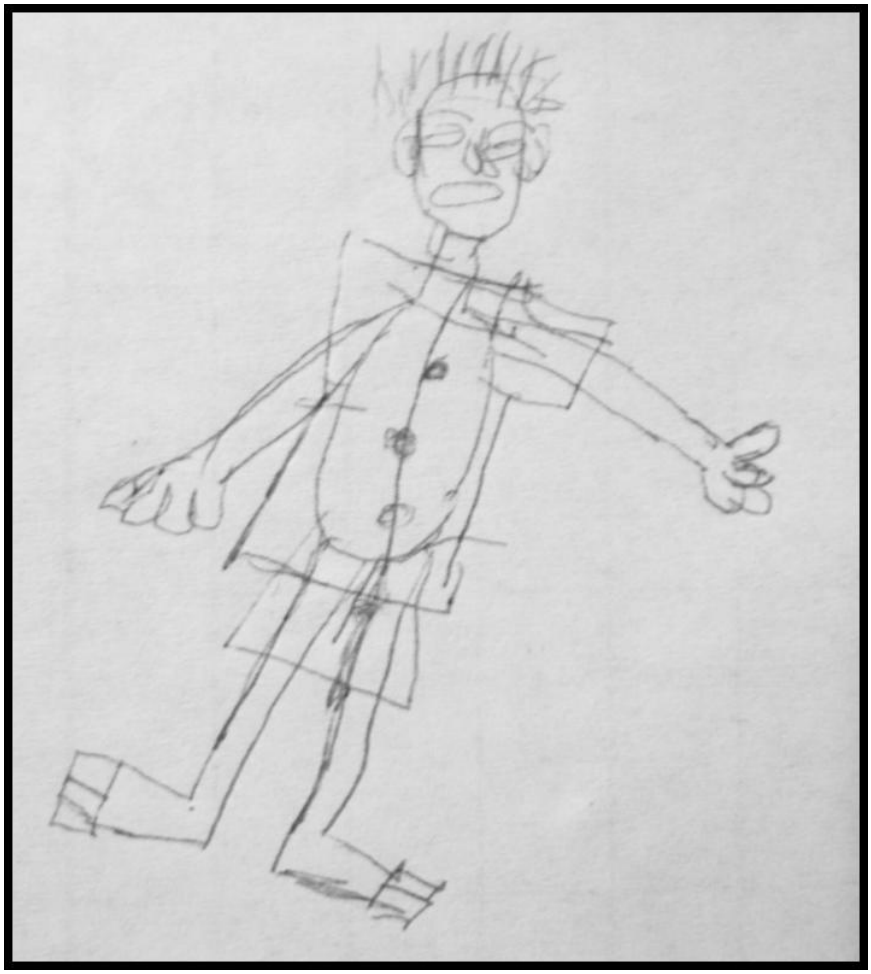

FIGURE 6